The Future for Health

everyone has a role to play

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Health Cluster Portugal
Pólo de Competitividade da Saúde

Foreword from the President of the Calouste Gulbenkian Foundation

THE HEALTH OF THE PORTUGUESE POPULATION has made a remarkable progress in the last few decades, a fact that was recognized internationally and is the most positive achievement of our forty-year democratic regime.

However we cannot ignore the limitations of our resources and how it affects our options. We are well aware of the need to prioritize our problems and the allocation of our resources. We must decide wisely, with boldness and courage.

The progress achieved in the health system is due to enlightened policies but also to scientific advances and technological innovation. However the progress in terms of life expectancy must be supported by discerning judgment, to ensure a fair and lasting commitment.

Right from the beginning, the Calouste Gulbenkian Foundation has sought to be part of this evolution, trying to grasp the different signs and adapting its intervention strategy in the Health area to what it believed, and still believes, better embodies a contribution to the quality, accessibility, and equity providing for health care.

Thus, what began as a residual and complementary action to public service – mainly supporting the outfitting and technological modernization of health units – has shifted since the late 90s to a more pro-active attitude, looking for answers to new problems and contributing to the identification and dissemination of best practices.

The Foundation has also sought to keep up with the significant shift of the intervention paradigm in the Health sector. This requires an approach beyond national boundaries, demanding the intervention of a wide range of actors and partnerships, multidisciplinary analysis and a close partnership between scientific research and clinical practice. We have therefore tried to be a catalyst of wills and synergies, national as well as international, so as to pave the way for changes and for adapting to new realities.

The Project "Health in Portugal: a Challenge for the Future" mobilized an exceptional number of leading national and international personalities to prepare a report on the structure of the health care system. The results, reported in this volume, are the Foundation's contribution to this challenge.

The Board of the Calouste Gulbenkian Foundation welcomes therefore the contribution of all members of the different teams who worked on this report: the Commission, the Advisory Board, the various working groups, the group of young professionals, the support team, and also all the institutions, bodies and leading personalities involved, as well as the suggestions that have reached us in various ways.

I want specially to acknowledge the work of Professors João Lobo Antunes, Pedro Pita Barros and last but not least Jorge Soares, director of the Gulbenkian Program *Inovar em Saúde*. Their absolute dedication and outstanding competence were of great benefit to the work done.

A special word of recognition is due to Lord Nigel Crisp, Chairman of the Commission, who generously applied his qualified experience, talent and enthusiasm in the leadership of this project.

Finally, the Foundation has made a commitment to start working on the three "Gulbenkian Challenges", presented by the Project's Commission. The purpose of this decision is not to engage in a short-term discussion, but rather to build a wide global commitment: the vision for the future of a strengthened and sustainable Health System for the new generations, in which we all have a role to play.

Artur Santos Silva

Foreword from the Commission

Dear President and Trustees

It has been a privilege and a pleasure to undertake this review on your behalf. We have received a warm welcome and generous help from everyone we have met during this process. This is undoubtedly due to the reputation and standing of the Calouste Gulbenkian Foundation, but it is also because so many people in Portugal are committed to the enduring vision of a high quality health system accessible by everyone in the country.

We have set out a simple vision about empowered citizens, an active society and a continual quest for quality and called for a new Compact for Health. This is supported by a new approach to implementation that literally has a role for everyone to play in improving health and well-being and in creating and sustaining the health system into the future. Achieving this will require farsighted and bold leadership which is able to set out the direction of travel, build public and political support and create a major programme of change. We believe that there is an excellent basis to build on in Portugal and that the country can position itself very well to take advantage of the developments in science and technology that we can all anticipate in the next 25 years.

We are delighted that the Foundation will support the three *Gulbenkian Challenges* we have proposed. Many of our other recommendations can start to be implemented in 2015 and begin to have an impact in 2016. We very much look forward to hearing about progress.

We wish to thank the many people who have assisted us and in particular the members of the 4 Working Groups which were so ably chaired by Maria do Céu Machado, José Pereira Miguel, José Carlos Lopes Martins, and Peter Villax. We are especially indebted to the project leader Sérgio Gulbenkian and his team of Lucy Irvine, Francisco Cluny, Francisco Wemans and Inês Mascarenhas; and to the lead Trustees, Isabel Mota and Diogo Lucena. We are also very grateful to Health Cluster Portugal for their support and for technical support from KPMG.

Yours sincerely

Lord Nigel Crisp (Chair)
João Lobo Antunes
Pedro Pita Barros
Donald Berwick
Wouter Bos
Ilona Kickbusch
Jorge Soares

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Key points

THIS REPORT CALLS for a new compact for health where everyone has a role to play – citizens as well as health professionals, teachers and business people as well as municipalities and national government.

Health is influenced by many different factors – from education, the environment and the economy to the quality of health services and the skills of health professionals. Looking forward 25 years we can expect enormous change as these factors interact in multiple ways to shape the future.

This change and complexity means there is a need to learn constantly and adapt as the future unfolds in order to take advantage of new opportunities and avoid new threats and risks. It also means that everyone must contribute to improving health and that every sector of society needs policies which help maintain and improve health. Health cannot be left purely to health professionals or politicians nor can it be treated simply as a business or a government service. Everyone has a role to play.

This report offers a new approach to improving health.

This report offers a new approach to improving health. It places the focus firmly on action by citizens and wider society. It aims to reduce the incidence of chronic diseases such as diabetes and the length of time that people suffer from them – both of which are higher in Portugal than in most Western European countries – and it shows how quality improvement methodologies and better access to evidence improve health services and reduce expenditure.

The report envisages a transition from today's hospital-centred and illness based system, where things are done to or for a patient, to a person-centred and health based one where citizens are partners in health promotion and health care. It will use the latest knowledge and technology and offer access to advice and high quality services in homes and communities as well as in clinics and specialist centres. This vision maintains the founding values of the SNS and builds on the strengths of the current system, the skills of health professionals and the achievements of the past – but it demands new approaches, different infrastructure and a lower and more sustainable cost base.

This report identifies 7 key elements needed to make this happen:

1.
A new compact for health. Change at this scale requires farsighted and bold leadership able to bring people together into a new Compact for Health, set out the direction of travel and build public and political support. It will also require a major programme of change – championed and led by an alliance drawn from the whole of society – with new systems for continually learning, assessing the evidence and implementing improvement. This needs to be supported by a temporary transition fund to cover the "double running" of facilities as the new system is introduced.

2.
Action by citizens. Health starts at home – people need to be much more involved in managing their own health and helping shape the whole system. Citizens need to own their health records, have information about the quality and costs of services and participate in decision-making.

3.
Action across society. Modern societies actively market unhealthy lifestyles – and modern environments make it difficult to make healthy choices. Action is needed from all sectors of society to improve health as well as from citizens and national and local government.

4.
The continuous pursuit of improved quality. Early treatment, high quality and evidence-based services are good for patients – and also reduce waste and save expenditure. There needs to be a focus on continuous quality improvement and to systematically applying the evidence of what works, everywhere and at all times. Portugal must position itself to take full advantage of future advances in knowledge and technology and develop its own biomedical research base still further.

5.
A person-centred and team-based health system. New service models are needed which provide integrated care for all individuals with particular emphasis on: chronic disease management; the development of more services in the home and local community; and the creation of specialist networks – based in reference centres but reaching all parts of the country through technology and shared protocols.

6.
New roles and strengthened leadership at all levels. Health professionals are well suited to be agents of change and improvement, but leadership is needed in communities as well as in health services and leaders need to work together. All health professionals need to take on new roles and work more closely together – with their education adapted accordingly – whilst patients and community organisations need support to take on greater leadership roles.

7.
Financial sustainability. The vast majority of costs in the health system come from caring for people with long-term chronic conditions. Financial sustainability will only be achieved though reducing the incidence of these diseases and the associated morbidity, developing new models of care for them and making sure evidence is applied systematically everywhere and waste reduced to a minimum. New financial mechanisms and outcome-based incentives can help if managed well; but the financial salvation of the system will depend on political willingness to introduce health into all policies, effective health promotion and concerted action by citizens, wider society and health professionals.

THE GULBENKIAN CHALLENGES

The Calouste Gulbenkian Foundation which set up this review has committed itself to playing its part by initiating three ambitious *Gulbenkian Challenges* which each exemplify the approach described in the report – showing what can be achieved – whilst tackling some of the most important challenges in Portugal. They are:

- Reducing hospital acquired infections – halving rates in 10 hospitals in 3 years
- Slowing the growth in diabetes – preventing 50,000 people getting the disease in 5 years
- Helping the country become a leader in early childhood health and development – with measurable improvements in the health and well-being of children in the longer term.

1

A new compact for health

This report envisages a transition from today's hospital-centred and illness based system, where things are done to or for a patient, to a person-centred and health based one where citizens are partners in health promotion and health care. It will use the latest knowledge and technology and offer access to advice and high quality services in homes and communities as well as in clinics and specialist centres.

Change at this scale requires farsighted and bold leadership able to bring people together into a new compact for health, set out the direction of travel and build public and political support.

A NEW VISION FOR HEALTH AND HEALTH CARE

The Commission's brief was to look forward 25 years to *"create a new vision for health and health care in Portugal, describe what this would mean in practice and set out how it might be achieved and sustained."*[1]

The Commission was established because, whilst there is widespread support for the continuation of an equitable national health system, there is also a general recognition that the current system, which has served the country so well, cannot satisfactorily meet the needs of the future in its current form. In looking forward the Commission was asked to focus in particular on *"the promotion of health and prevention of disease; the provision of more varied community based and integrated services to meet the needs of the growing number of people with long-term conditions; greater participation of citizens and patients; and the potential impacts of new knowledge and technologies."*[1]

The Commission's approach to its task was based on an understanding that health is determined by many different variables – the so-called determinants of health – which range from education, commerce and the economy to the quality of health care and other public services.[2] These interact in complex and multiple ways which change over time. This level of complexity and change brings with it a need to take action on many different fronts and to be constantly learning and adapting as circumstances change. It also means that there need to be many people involved in making improvements – institutions as well as individuals – to shape and lead changes in their own areas, whether they are municipalities, businesses, professional associations or citizens' groups. There is a role for everyone to play.

The work of the Commission has been designed accordingly to be as inclusive as possible: meeting with stakeholders, establishing Working Groups and Advisory bodies, holding conferences and meetings and drawing on expertise and evidence from within Portugal and abroad as shown in Figure 1. This ensured that the Commission's work was well grounded in Portuguese experience and culture; generated cross-cutting ideas for integrated approaches to improvement; and helped build ownership for the process and create the necessary momentum for change.

Figure 1 • **Process**

PROCESS

The Commission adopted an inclusive process:

- Creating four Working Groups which covered the following areas:
  1. Working Group 1 – Health Services and Public Health
  2. Working Group 2 – Citizens and the SNS
  3. Working Group 3 – Staffing the Service
  4. Working Group 4 – Harnessing knowledge, technology and innovation
- Setting up an Advisory Board made up of senior representatives of stakeholders in the health sector and a Young Professionals Advisory Group.
- Meeting with stakeholders
- Holding conferences to discuss the Working Groups' reports and best practices
- Collecting evidence on policy and best practice from Portugal and elsewhere

In looking forward the Commission has been very conscious of the importance of building on what already exists – going wherever possible with the flow of current policy and practice – rather than trying to start everything anew. There needs to be continuity and a pathway from today's reality to tomorrow's vision. Portugal is very fortunate in having a great deal to build on. It has a good SNS with high standards and generally good services and there is a profound and important ethical tradition of public service as well as high levels of skills amongst health workers.

Portugal also has a deep and very widespread support for the continuation of an equitable national health system, accessible by all citizens and based on principles of social solidarity. The Commission fully supports this position and has embraced the values of the SNS within its thinking – with their emphasis on universality, equity and social solidarity. These values, in the form they were published in the National Health Plan for 2012-2016, are shown in Figure 2 and have informed the Commission's work and recommendations.

Figure 2 · **The values of the SNS** [3]

THE VALUES OF THE SNS

- **Universality** – no one is excluded from healthcare
- **Access to quality care**
- **Equity** – everyone has equal access to care and entitlement to health outcomes, according to their needs, regardless of gender, religion, ethnic origin, age, social status or ability to pay for such care
- **Solidarity** – the financial arrangements of the health system guarantees everyone access to health care

Discussions with stakeholders also revealed remarkable agreement both about the broad shape of the vision for the future and about the need for radical change. The Commission therefore concluded that the greatest challenge facing Portugal was not how to describe this vision but how to achieve it – how to identify the essential strategies and steps to be taken and how to ensure that they were implemented.

Many reviews and health reforms start by looking at finance and economics and at the internal processes of the health system. The Commission, however, has very deliberately not started with finance or the health system but with the values that underpin the system and with an exploration of what is needed in terms of health care and to stay healthy by individuals and the population at large and how this can be achieved. Finances and internal processes are dealt with later, as part of the tools to achieve the desired goals.

The Commission's approach is also very different when it comes to implementation. The complexity of the system means that there needs to be a continuous process of learning and adaptation as policies are implemented and their results seen. It is no longer possible, if indeed it ever was, to plan out a policy in detail and implement it without regard to the impacts on other parts of the system. There is no longer space for this sort of straight line thinking where each action or intervention produces a simple result. Everything has multiple impacts. The introduction of a new working practice in primary care, for example, affects the whole system: so, too, do rises in unemployment, changes in education or changes in consumer behaviour.

Diabetes provides a good example. This is a particular challenge in Portugal, where its growth is associated with social and economic changes, ageing, dietary and exercise patterns. Reversing this trend will require integrated action across a broad front – with health being part of all relevant public policies – and applying evidence of what works where this is known, but also evaluating and learning as the results of interventions are seen.

This new approach is all about leadership and managing change. Ultimately, success will depend on as many people as possible sharing in that leadership and management as partners in a new compact for health.

TODAY'S REALITY

Portugal has a good foundation to build on for the future. However, the Commission has undertaken its task at a time when Portugal and its health system have been going through a very difficult period. Most of the population have experienced a reduction in their standard of living, with associated effects on their health and well-being. Whilst these impacts have not yet been quantified, the Commission has heard reports of growing mental health problems, increased addictions and of schools staying open in the holidays in order to ensure that children were fed properly.

At the same time, public sector workers, including health workers in the SNS, have had their pay reduced by around 15% and seen their future pensions fall in value. Staff numbers have reduced whilst demand for health care has increased. There are unemployed nurses and many young people and some older ones are leaving the country for better prospects elsewhere.

Despite these enormous pressures, the health system has proved to be remarkably resilient with services and standards largely being maintained thanks to the determination and efforts of health workers throughout the country. The economy is starting to grow again; however, there will be long-term consequences from the problems of the last few years. The Commission is very conscious that the country needs to anticipate and plan for increased health needs amongst those most affected by these problems. Portugal is not alone, a recent report for the Bureau of European Policy Advisers of the European Commission foresees that growing inequality – in part a consequence of the financial

Despite these enormous pressures, the health system has proved to be remarkably resilient with services and standards largely being maintained thanks to the determination and efforts of health workers throughout the country.

crisis – will become the biggest challenge facing Europe as the acute phase of the crisis fades. It argues that European policy needs to focus much more on socio-economic health, not wealth, in planning for the future.[4]

Portuguese development and policy are closely linked with wider European and global policies and developments including the WHO's *Health 2020 Framework for Action*. The Commission has therefore located its analysis and recommendations within the framework of these policies, garnering ideas from them and learning as appropriate. It also recognised that there is a much wider development of ideas and approaches currently underway that goes far beyond health and Portugal and which concerns the re-negotiation and redesign of the European *welfare state* and social solidarity systems which were developed after the Second World War. This was well articulated in an OECD report on Portugal published in 2012 which states:

"Reforms of the State would also contribute to making the Government more responsive to the needs and demands of the population, by ensuring that public resources are used more efficiently, by improving the quality of public services and public administration, and by ensuring that the costs and benefits of adjustment are shared more equitably. This strengthening of the link between Portuguese citizens and their Government will in turn build support for comprehensive structural reforms". [5]

This report needs to be read in this wider context and as contributing to these changes.

LOOKING FORWARD 25 YEARS

The Commission was asked to look forward to the 2040's in making its recommendations. It is, of course, impossible to predict with any degree of certainty how the future will look in 25 years' time. There will undoubtedly be massive social change and we can anticipate changes in the global balance of power as well as developments in science and technology the details of which we can't yet imagine. We can, however, reflect on how current trends might develop over this period; whilst noting that we cannot predict the disruptive events, discoveries or inventions – the "*black swans*" – that may take Portugal and the world in completely unexpected directions. [6]

There are many positive trends affecting health care both globally and within Portugal. There are the advances in science and technology that promise to bring new therapies, new diagnostics and imaging, personalised medicine, and the precision of robotic and nano-technologies. Portugal has a good bio-medical research base to build on and has grown its research capacity over recent years.[7] These developments have the potential to offer much better understanding of how to prevent disease and promote health.

Permanent on-line communication will make this knowledge available to the professional and the citizen wherever they are in the country or the world. Portugal with its *Via Verde* motorway toll system, for example, and high use of mobile telephones is an early adopter of new technologies. More diagnosis, treatment and care can take place in homes or the community. These developments will occur at the same time as educational standards in the general public are improving and there is greater awareness of healthy and risky behaviours. Healthy cities and healthy schools programmes are growing and towns and schools can become healthier. More people will be better able to self-care and provide support to others. Governments globally are also giving health a greater priority and becoming more willing to act independently and together on health threats such as tobacco use and anti-microbial resistance.

Equally, there are many negative trends. Portugal will face shared global risks such as climate change, drug-resistant infections and pandemics. In common with most of the rest of Western Europe, Portugal has an ageing population and a declining birth rate. Unemployment has hit young people very badly and, as we have noted, there are high levels of migration. There is the trend towards growing inequality in Europe whilst the economic crisis is having the biggest impact on the poorest. There are strong commercial forces promoting unhealthy foods and, as described in Chapter 3, modern society actively markets ill health. There are increasing levels of obesity. There is a big growth in long-term conditions or chronic diseases – particularly diabetes, cancer, respiratory and cardiac diseases – that are debilitating for the sufferer, may be ultimately disabling and will affect economic growth. The existing hospital based infrastructure in most Western countries is not well suited to managing these diseases and needs to change to a more community based system. New technology, rising expectations of health care and technology in OECD countries have driven costs higher in recent years and may be expected to continue to do so in the future.[8]

The report will examine these trends, as described in Figure 3, in the following chapters. All of them are common to other European countries; although some, such as the ageing population, the length of time people are unhealthy during their lifetime and the growth in obesity amongst young people and diabetes in the population as a whole are particularly pronounced in Portugal. As will be seen in Chapter 2, Portugal has about 5.4 million people with one or more chronic

Figure 3 · **Positive and negative trends for the future**

POSITIVE TRENDS

- Biomedical science and technology
- Information and computer technologies
- Better evidence for disease prevention
- Improved education
- Greater awareness of health risks
- Government action on health

NEGATIVE TRENDS

- Ageing population with low birth rate
- Widening inequalities in society
- Growth in long-term conditions
- Outdated models of care
- Increasing health care costs
- Marketing of unhealthy products

diseases and Portuguese women over 65 can anticipate on average only 6.6 more years of healthy life. Norwegian women, can expect 15.4. Much of the action in this report is aimed at improving these figures.

It is possible to develop many different scenarios from analysis of these trends: ranging from the very positive and optimistic to the negative and cataclysmic. A number of recent studies have done this in order to show the extent of the change that is needed.[9] The Commission's approach has been to ask the question: how can Portugal secure for itself the best of these many possible futures? How can it avoid the worst? What are the steps that can be taken now to set the country on a path that will lead towards a future where it has a sustainable and equitable health system which can take advantage of the new knowledge and technology, promote health for younger and older people alike, whilst controlling costs?

What is clear from all the debate in Portugal and observations in other Western countries is that major change is needed if Portugal – and other countries – are to be able to continue with the same sort of high quality and publicly accessible health system that they have at the moment.

SUSTAINABILITY

The sustainability of the system is crucial. Whilst financial sustainability is discussed in Chapter 7, the Commission identified five non-financial features which it sees as the conditions necessary for a sustainable system in the future. These conditions are shown in Figure 4.

The first three conditions for sustainability are about building up the resilience and strength of individuals, communities and society. Firstly, a sustainable system will be one where people themselves are healthy and robust, better able to fight off disease and ailments. Secondly, it will be one where there are strong networks of informal caring – from families, neighbours and communities – which can limit the burden on the formal systems. Thirdly, health policy and practice need to be well integrated with other social and economic sector policies and practices to gain synergy, reduce duplication and ensure a balanced approach to quality of life and to public expenditure. There needs on the one hand to be legislation and control over the harmful effects of tobacco, pollution and unhealthy foods and, on the other, the ability to deliver services in an integrated fashion.

The next two conditions of sustainability are about the operation of the health system itself. A sustainable system will be one that is well designed and fit for purpose which operates efficiently with little waste. Finally, sustainability will also depend on there being a productive workforce of adequate size, appropriately trained and supported to meet the needs of the population.

These conditions describe circumstances which are dynamic and constantly changing. Where family structures and informal social networks which support elderly relatives break down, for example, the burden falls on the formal system. Where new organisations of people with similar conditions are created, on the other hand, they can provide support which can help prevent acute episodes and reduce the need for clinical intervention.

The need to create and maintain these conditions has influenced the Commission's thinking and is reflected in the following chapters and in its recommendations.

Figure 4 • **Conditions for sustainability**

THE CONDITIONS FOR SUSTAINABILITY

A sustainable health and care system which is affordable both by the country and individuals requires 5 key elements to be in place:

1. A healthy population
2. Strong resilient communities with good informal networks of care
3. Health policy and practice need to be well integrated with other social and economic policies and practices
4. A well designed people centred health and care system, fit for purpose and efficient
5. Adequate staff, trained and working together in teams to achieve integrated care

VISION

The Commission found remarkable agreement both about the broad shape of the vision for the future and the necessity for radical change. People talked about needing greater emphasis on disease prevention; about change from a hospital and professional based system to a community and person based one; about patient empowerment and health literacy; about telemedicine and personalised medicine; about healthy societies and environments; and about cultural change from sheer paternalism to responsible partnership. Many people also talked about the need for better information and greater transparency.

Different people brought their own personal emphasis. Working Group 2 offered a patient perspective, the full version of which is reproduced in Appendix 2:

> *"In my ideal health system, I am healthy from my safe and peaceful birth to my dignified death, late in life, surrounded by my family. I have very little reason to interact directly with the system itself physically, apart from preventive measures, like vaccines or screening, and rare acute situations like unavoidable illness or accidents. When I have to go to a Wellness Centre for proactive health care or a hospital for urgent treatment or serious medical issues, my problem is solved professionally and with humanity at that location, in as little time as possible."* [10]

Working Group 4 described a similar future where technology played a very significant role and, later in the same document, described how this benefited both the individual and the Portuguese economy:

> *"In order for this to take place, a change in vision is crucial – from a provision and hospital-centred system to a new, prevention oriented and citizen-centred one, supported by a restructuring of the health system based on an intelligent and rational use of technology, ICT in particular. (…) Thus, the health system ceases to be a network of professionals and infrastructures (namely hospitals or health centres) where we go when we are sick, and becomes a larger network that includes each one of us as citizens (healthy or unhealthy), as well as the relevant professionals and infrastructure for the prevention and assurance of health."* [11]

Additionally, whilst the Ministry of Health has had to focus on finances and the requirements of the Memorandum of Understanding agreed with the *Troika*;[12] the National Health Plan for 2012-2016 contains many statements of intent and policies about the longer term future. In March 2014 it published the implementation section for this Plan and stated its mission:

> *"To maximize health gains by aligning around common goals, integrating the sustained efforts of all sectors of society, and implementing strategies based on citizenship, equity and access, quality and sound policies."*[3]

These themes are all consistent with the ideas being developed and discussed in other countries. They are also consistent with the idea of linking health with a wider notion of well-being. This is not a new idea. The preamble to the constitution of the World Health Organisation of June 1946 says that: "*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*"

The concept of well-being has been developed and expanded in recent years with, for example, the OECD creating a new Index of well-being based on measures which include health but also include education, wealth, psychological well-being and community coherence.[13] Throughout this report the Commission frequently refers to health and well-being together unless the context is very clearly health specific.

The key challenge, the Commission concluded was not how to describe the vision but how to achieve it: the challenge of implementation. It has therefore chosen to describe a vision for the future, shown in Figure 5, which has three elements, each of which is itself a major lever for bringing about change.

Figure 5 · **Vision for the future**

THIS VISION IS FOR A FUTURE WHERE:

1. Citizens are able to play a far greater role in their own and their family's health and in improving health in society
2. All the structures and sectors of society – education, environment, social security, commerce and employment as well as health – work together to promote health and well-being
3. There is a commitment to continually improving quality and to applying knowledge and technology systematically in support of health and well-being

This vision represents a transition from today's hospital-centred and illness based system, where things are done to or for a patient, to a person-centred and health based one where citizens are partners in health promotion and health care. It will use the latest knowledge and technology to support health promotion and improvement and to deliver high quality services reliably in all parts of the country.

THE DRIVERS OF CHANGE

The health and well-being of the population are influenced by many different factors. It is important in this kind of complex system to identify the key drivers which will bring about positive change across the whole system.[14] In the context described here it is these drivers that will make sure that Portugal takes the first steps towards the most positive future in 2040 rather than the negative one. Through its work the Commission has identified 7 drivers which between them will lead to improvement. These are the key strategies for change:

1. **A new compact for health**. Change at this scale requires farsighted and bold leadership able to bring people together into a new compact for health, set out the direction of travel and build public and political support. It would be accompanied by a major change management programme which is supported by new systems for continually learning, assessing the evidence and implementing improvement as well as a temporary transition fund to meet the cost of double running as the new system is developed.
2. **Action by citizens**. Health starts at home – people need to be involved in managing their own health and helping shape the whole system. Citizens need to own their health records, have information about the quality and costs of services and participate in decision-making.
3. **Action across society**. *Modern* societies actively market unhealthy lifestyles – action is needed from all sectors of society to improve health as well as from citizens and national and local government.
4. **The continuous pursuit of improved quality**. Early treatment, high quality and evidence-based services are good for patients – and also reduce waste and save expenditure. There needs to be a focus on continuous quality improvement and systematically applying the evidence of what works, everywhere and at all times.
5. **A person-centred and team based health system**. More care will take place outside hospital in the home and community, supported by new science and technology. Primary and community care need to be strengthened and specialist networks developed – based in centres of excellence but reaching everywhere through technology and shared protocols.
6. **New roles and strengthened leadership at all levels**. Health professionals are well suited to be the main agents of change and improvement – but leadership is needed in communities as well as in clinical services. Professionals need to take on new roles – with their education adapted accordingly – whilst patients and community organisations need support to take on greater leadership roles.

7. **Financial sustainability**. The vast majority of costs in the health system come from caring for people with long-term chronic conditions. Financial sustainability will only be achieved though reducing the incidence of these diseases and the associated morbidity, developing new models of care and making sure evidence is applied systematically everywhere and waste reduced to a minimum. New financial mechanisms and outcome-based incentives can help if managed well; but the financial salvation of the system will depend on political willingness to introduce health into all policies, effective health promotion and concerted action by citizens, wider society and health professionals.

This and the next 6 chapters each address one of these drivers and contain a small number of recommendations for action. Chapter 8 lists all these recommendations whilst Chapter 9 sets out *three Gulbenkian Challenges* which will help accelerate implementation.

MANAGING CHANGE AND CONTINUOUS LEARNING

This positive future described in the vision of healthy citizens, a health promoting society and continuous quality improvement won't happen by itself but needs to be actively planned for and managed. Implementing it will require major change in what will amount, over time, to the redesign of the whole health system to achieve different goals, function differently at all levels, and operate with different infrastructure and a different cost base. Change will take a long time but needs to be started now.

The Commission believes that a major programme of change is required in order to set Portugal on the best path for the future. Clearly, it is not possible to plan change in any detail over 25 years but, as described above it is perfectly practical to use key drivers to influence and shape the direction. Managing their application well requires political and public support as well as leadership from many different organisations and individuals. There needs to be a shared vision of what the future will look like that is sustained over years. It will in effect be a new compact for health. There also need to be new methodologies and some new infrastructure. The report makes four recommendations on this covering:

- A new compact for health
- Access to and use of evidence
- Quality improvement and implementation
- Funding the transition

A NEW COMPACT FOR HEALTH

Political leaders have a major role to play in health both through Parliament and, when in government, in creating the framework within which the whole health system operates and in the leadership of the SNS in particular. They will need to set out the direction of travel for the health system and build political and public support for the necessary changes – preferably with as much cross-party support as possible. Parliament may wish to consider whether it should give more emphasis to the role of the Health Committee so that it can take a broader oversight of developments.

Whilst political will and leadership is important, the new future envisaged in this report means that others from across society also have major roles to play. The Commission believes that there is a need for a new compact for health which recognises the major changes needed in the future. Since its foundation, the SNS and the wider health system have provided an extremely valuable role in looking after the health of the population and providing services to and for patients. In the future, as this report argues, citizens must be active partners in promoting and protecting health and in delivering and shaping health care. The old implicit social contract where things are done to and for the population needs to be replaced by a new compact for health where all are participants.

The Commission suggests that the Government should initiate the creation of the new compact but leave the proposed National Health Council described below to develop it and consult on its final form. The key features of the proposed compact are outlined in Figure 6 and described in the following paragraphs.

Figure 6 · **Key features of a new compact for health**

KEY FEATURES OF A NEW COMPACT FOR HEALTH

- Citizens as partners and participants
- Health professionals providing their knowledge and skills – ensuring evidence, high standards and scientific rigour are applied
- Organisations throughout society aligning their policies and practices to promote health and prevent disease
- Government creating the structure and framework for a high quality sustainable health system
- The National Health Council – a whole of society alliance – owning the compact and the vision for the future and advising on policy

As part of this a new national body is needed which can own the compact and refine the vision for the future, take an overview of the system and advise on policy in line with this compact and vision. It should embody the compact in its membership by being representative of citizens and all sectors of society, independent of politics, and report to Parliament, the Government and the public.

This builds on a recommendation from Working Group 1 which noted that there was already legislation which enabled the establishment of a National Health Council but which had never been implemented. It noted that as it stands this Council would represent interested parties in the health sector, including patients, but did not include all the groups that influence and are influenced by the health and care sector. It stressed the importance of:

> *"Governance for Health in the formulation of policies (health, social, educative, environmental, economic and financial), strategies and national health plans includes wide participation of government sectors and society allowing the alignment of decisions with the real health needs of the population".* [15]

The Working Group went on to propose the creation of a Whole of Society Alliance for Health which could bring all these parties together. Its full recommendation on this is shown in Appendix 3.

In building on this proposal the Commission recommends that the National Health Council should be an advisory body which would affirm the founding values of the SNS, endorse or amend the vision described here and adopt an explicit set of design principles for a high quality and sustainable health and health care system. These values, vision and principles could then be used to inform its advice. A suggested list of principles is described in Figure 7.

The Working Group went on to propose the creation of a Whole of Society Alliance for Health which could bring all these parties together.

Figure 7 · **Design principles for a high quality and sustainable health and health care system in the 21st Century**

A HIGH QUALITY AND SUSTAINABLE HEALTH AND HEALTH CARE SYSTEM IN THE 21ST CENTURY NEEDS TO BE:

- **Broadly based** – built on a shared vision that addresses all the determinants of health
- **Values driven** – ensuring that the whole population is provided for equitably
- **Inclusive** – involving all sectors of society in a new social compact for health
- **Accountable** – with clarity about responsibilities, authority and reporting to the public
- **Open and transparent** – with citizens owning their own information and able to access information on the quality and costs of services
- **Person -centred** – where care is compassionate and safe, integrated and personalised for each individual and with patients fully involved in decision-making
- **Local and accessible** – with services, wherever possible, provided in the home or local community and decision-making devolved as locally as possible
- **Partnership and team-based** – ensuring cooperation and knowledge sharing amongst clinicians, other health professionals and with citizens and partners
- **Evidence-based** – with evidence available and used throughout the system
- **Focussed on continuously improving quality** – and on implementation and learning
- **Resourceful and economical** – making the best use of available resources and avoiding waste

This proposal for a National Health Council complements the roles played by the Minister of Health and others in leading and managing the SNS. A later recommendation in this report calls for clarification of accountabilities in the supervisory and management structures of the health system. The two elements – an advisory body that brings all sectors together and the executive structure that provides supervision and management – both need to work well in order to offer the leadership and direction that the whole health system needs and to deliver this major programme of change.

ACCESS TO AND USE OF EVIDENCE

Turning to the importance of access to evidence, the Commission has noted the continuing development of clinical guidelines in Portugal and the need to create stronger systems for assessing new technologies and therapies. These are dealt with in more detail in Chapter 4. The Commission believes, however, that all these elements should be brought together into a new agency as an essential part of the new infrastructure that is needed to support these changes.

The agency, called here SNS Evidence, would be charged to continue the development and dissemination of clinical guidelines and the assessment of new and existing therapies. It would be responsible not only for developing guidelines and undertaking assessments but also for publicising the results to the public as well as to clinicians. This proposal is described in more detail in Chapter 4.

QUALITY AND IMPLEMENTATION

As regards implementation, Portugal, like other countries, has had many policy initiatives over recent years and, like other countries, seen many changes as Ministers and Governments have come and gone. The most successful implementations, such as the improvements achieved in perinatal mortality, have been sustained over time and across administrations although this has not been the general rule and the Commission is aware of many policies that have not been fully implemented or subsequently evaluated.

The Commission noted that there is no standard or agreed approach to implementation in Portugal. Typically, it has been left to "champions" and their powers of leadership and persuasion. Reliance has been placed on having good policy and research and on education and training rather than on active interventions. This is in contrast to developments in the science of implementation elsewhere. Some countries and systems have adopted a methodical and systematic approach to implementation. Wales, for example, has defined an approach which is being rolled out across the country so that any planned change, whether initiated nationally or locally, is undertaken in a specific fashion.[16] Kaiser Permanente in the US has a very developed approach to introducing

> As regards implementation, Portugal, like other countries, has had many policy initiatives over recent years and, like other countries, seen many changes as Ministers and Governments have come and gone.

innovations and challenges with its own internal change agents and testing centres as well as widely shared methodologies.[17]

Portugal needs to develop a shared approach to implementation and ensure that it is adopted across the system. Crucially, the Commission has also concluded that it needs to create an expert agency to identify and spread good practice and support implementation. It should work with health and other bodies to create and endorse shared methodologies for quality improvement and implementation; facilitate training and be able to offer advice and support as necessary. This approach is described further in Chapter 4 where a recommendation to this effect is included.

Portugal needs to develop a shared approach to implementation and ensure that it is adopted across the system.

FUNDING THE TRANSITION

Finances and financial sustainability are dealt with in some detail in Chapter 7. However, change management will require some investment. As the programme is implemented there will be a need to invest in the community – in long-term care, primary care, palliative care and elsewhere. In principle, most of this investment should be able to come from reductions in hospital costs. The Commission recognises that there will undoubtedly be delays in releasing funds and that there will inevitably be a period of "double-running" when community based services are duplicating hospital based ones.

In these circumstances the Commission recommends that the Government creates a transition fund to help manage the change. This will be need to be very tightly managed – with good business planning and project management – but should in the longer term be the most efficient and cheapest way to manage the vital transition that needs to take place over the next 25 years.

RECOMMENDATIONS

The following four recommendations are designed to provide the necessary leadership and infrastructure to manage change effectively and develop the new system that is needed in Portugal.

In making these recommendations, the Commission is very conscious that it does not want to add new costs and overheads to the system. It believes, however, as it argues in Chapter 5, that there is scope to reduce the number and size of existing national bodies in ways that will more than cover additional expenditure here.

Figure 8 · **Recommendations**

RECOMMENDATIONS

1. **A NEW COMPACT FOR HEALTH.** A new compact for health should be established which describes the new relationships and roles needed in the transition from today's hospital-centred and illness based system, where things are done to or for a patient, to a person-centred and health-based one where citizens are partners in health promotion and health care.
2. **NATIONAL HEALTH COUNCIL.** The National Health Council should be established as a whole of society alliance which should own and develop the Compact for Health and refine the vision for the future, take an overview of the system and advise on policy in line with this vision. It should be representative of citizens and all sectors of society and independent of politics and report to Parliament, the Minister of Health and the public.
3. **SNS EVIDENCE.** SNS Evidence should be created as a new agency, which brings together the existing programme of clinical guidelines with a new process for assessing new technologies and therapies, and ensures that evidence is available everywhere within the system at all times. The agency should make its deliberations and findings open to the public so that they as well as clinicians are able to see the evidence.
4. **TRANSITION FUND.** A transition fund should be created that can help support the costs of "double running" and the other interim costs of developing a health system with better chronic disease management, more services in the home and local community and specialist networks reaching all parts of the country.

EVERYONE HAS A ROLE TO PLAY – THE *GULBENKIAN CHALLENGES*

The approach described here requires more inclusive ways of developing policy, better processes of implementation and new systems for constant learning, evaluation and adaptation. It also requires everyone to play their part. The Calouste Gulbenkian Foundation has committed itself to playing its part by initiating three *Gulbenkian Challenges* which each exemplify this approach – showing what can be achieved – whilst tackling some of the most important challenges in Portugal. These are described in more detail in Chapter 9 and outlined in Figure 9.

Figure 9 · ***The Gulbenkian Challenges***

THE GULBENKIAN CHALLENGES

- Reducing hospital acquired infections – halving rates in 10 hospitals in 3 years
- Slowing growth in diabetes – preventing 50,000 people getting the disease in 5 years
- Helping the country become a leader in early childhood health and development – with measurable improvements in the health and well-being of children

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Action by citizens

2

Health starts at home – people need to be much more involved in managing their own health and helping shape the whole system. Citizens need to own their health records, have information about the quality and costs of services and participate in decision-making.

HEALTH STARTS AT HOME … AND IN THE FAMILY, THE COMMUNITY AND SOCIETY

This simple statement will resonate with generations of Portuguese mothers who know very well the virtues of home made soup and other food and how to make their families strong and healthy. It also makes abundant sense to today's researchers who have shown how vital the first 5 years of life are for future health and how important it is that children have the right social and developmental experiences during these years.

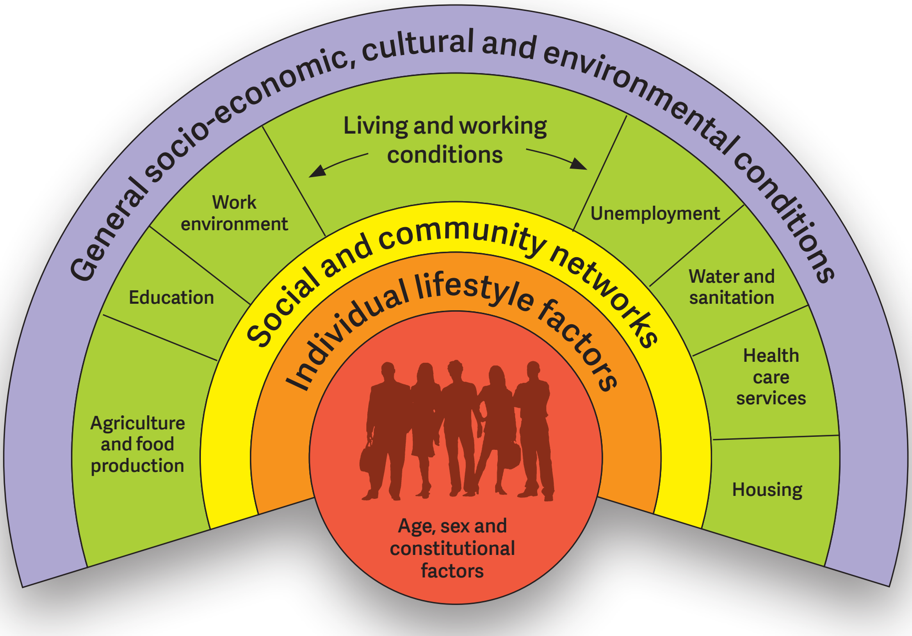
The *creation* of health is important throughout life as well as in childhood, and is as relevant for healthy working age adults and healthy older people. The latter may need more professional help for illnesses and long-term conditions, but they also need to continue to build their own strength and *create* their own health.

THE DETERMINANTS OF HEALTH

The starting place for this chapter is the understanding that there are many things which combine together to determine the health of an individual. Figure 1 illustrates the main determinants of health – from the personal characteristics at the centre of the figure to the general socio-economic, cultural and environmental factors at the outer edge. All play their part in shaping the health of individuals, families and communities.

This figure underpins the work of the Commission and shows why it has taken such a very broad perspective on its work. Improvements in health can come from changes in any of these individual determinants but will be even more effective where positive changes are brought about in several areas at the same time. It recognises that changes to the health system, for example – whilst vital for individuals at particular moments in their lives – will only have a partial impact on the long-term health of the whole population.

Figure 1 · **The determinants of health**



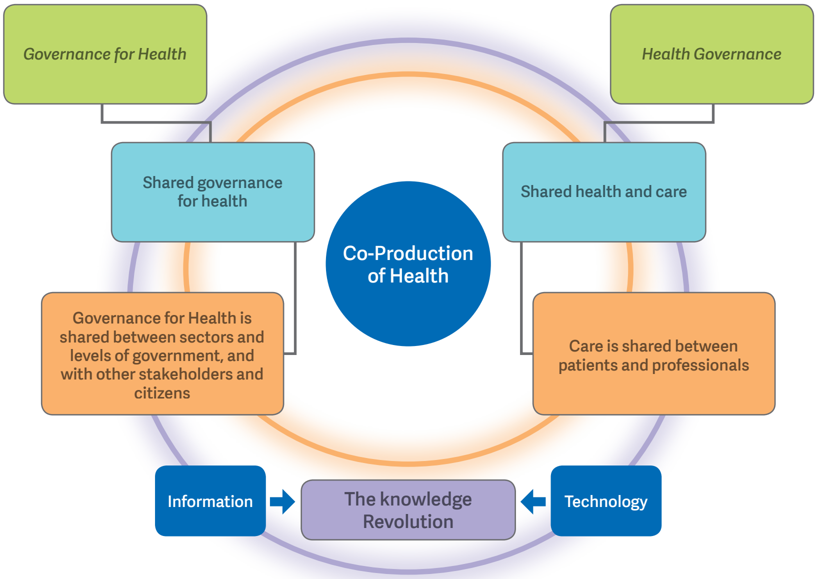
Source: Dahlgren and Whitehead, 1991

THE *CO-PRODUCTION* OF HEALTH

This chapter concentrates on *creating* health and on what individuals and their families, carers and friends can do. It should be read together with the following chapter on *Healthy Society* which examines how the wider social and economic structures of society can be better aligned to achieve improved health and well-being. These two issues – citizens becoming more active in health and all the structures and sectors of society working together to promote health and well-being – are at the core of the Commission's vision for the future. Together they can *co-produce* better health in Portugal.

Improvements in health and well-being will come from actions taken by citizens and families but they also depend on society enabling those actions and providing a health promoting environment. The two parts of this are well represented by the diagram in Figure 2 which shows on the left hand side how institutions and organisations need to work together to create a healthy society and on the right the way citizens need to work together with their clinicians and others within the health system.

Figure 2 · **Co-production for health**[1]



HEALTH STARTS AT HOME

Health starts at home and in the family, the community and society very neatly summarises the approach taken throughout this report that everything should start from the idea of *creating* health and developing a robust and resilient population that is better able to withstand disease and trauma. It reflects Portuguese traditions. During its consultations the Commission was reminded by patients groups of the importance of nurturing, caring and developing good habits in the home as well as of the importance attached to nutrition as a way of building strength and fighting illness. These approaches have a good basis both in the physical and in the social sciences.

The Barker (or thrifty phenotype) hypothesis is that reduced growth of the fetus in the womb is strongly associated with a number of chronic conditions later in life, including coronary heart disease, diabetes, stroke and hypertension.[2] If the mother lives in an environment with poor nutritional conditions – poverty, food shortages or poor diet – the baby will develop so that it is prepared for life where resources are short, resulting in a 'thrifty phenotype.' If this baby then grows up in a world where, in fact, it has adequate nutrition (or an oversupply of fatty and sugary manufactured foods) it will be particularly ill-suited to this kind of diet. The thrifty phenotype baby growing up in a rich country today, for example, is more likely to develop diabetes than babies whose mothers were well nourished during pregnancy. Before birth, insulin commands the baby's growth, ensuring that the speed of growth matches the availability of food. When mothers are undernourished the cells that produce insulin do not function properly, and are less able to make insulin and meet the challenges of managing the body's sugar, leading to diabetes and other related problems such as obesity. The Barker hypothesis is widely (though not universally) accepted, and means that a key priority in addressing chronic disease should be the welfare, education and nutrition of young and pregnant women.

Health starts at home and in the family, the community and society

This is also supported from a social and psychological perspective. Children raised in supportive family environments, with positive attitudes towards exercise, healthy eating and creative learning are happier, more productive and *healthier* throughout their childhood and adult lives. Research reviews have found strong evidence that familial attitudes and food available in the physical environment, as well as the media and peer factors, have significant impacts on children's and young adult's healthy eating behaviour.[3] Sir Harry Burns and others have drawn attention to the positive effects that seemingly simple efforts such as reading children bedtime stories has on their developmental milestones.[4]

The impact of this in Portugal can be seen in two examples, one positive and one negative. The positive one is the way in which Portugal has improved its child mortality levels over the years until they have become amongst the very best in Europe. This success will be discussed in the next chapter but it is sufficient to say here that it was achieved through a wide-ranging effort from improving the health of mothers, to the introduction of more effective clinical practices and procedures. It was about creating the conditions for childhood survival and lifelong health. We will propose in the following chapter that Portugal should build on this success and aim to become a world leader in children's health and well-being.

The negative health impacts of deprivation in childhood can be seen today in the relatively high incidence of bowel and stomach cancers amongst older people in Portugal, which is a direct legacy of poor nutrition and other deprivations when they were growing up 50 or more years ago. The impoverishment of many

Portuguese in the last century has left its mark on the long-term health of the population.

As noted earlier, this concept of the *creation* of health is important throughout life as well as in childhood, and is as relevant for healthy working age adults and healthy older people.

HEALTH AND CARE

The Commission also wants to emphasise the importance of carers and family members. Women, in particular, currently play a very large role in caring for relatives and neighbours. This inhibits their ability to take on employment and other roles in society. Estimates suggest that the value of this care, if converted into money, would match or exceed the Euro 7.5 billion (thousand million) of public money spent each year on the SNS. Recent estimates from the UK indicate that informal carers who look after relatives or friends are saving the nation £119 billion a year, or almost as much as the entire cost of the UK's NHS.[5] This estimated value has risen very significantly in recent years, a sign of the growing number of people who are taking on caring responsibilities.[6]

This enormous value shows how important this caring is as a complement to the formal health system and how it can take pressure off the NHS. If these informal systems fail, the burden will fall on the formal health and care system. Work flexibility is important for both mothers and carers, allowing them to remain in the labour force and earn income to support themselves and those they care for. Portugal has one of the lowest levels of part time work options in Europe, meaning Portuguese informal carers may face particular difficulties in returning to work or meeting their needs.[7]

> It is equally important that there are good links between these informal systems and the formal health and care system.

It is equally important that there are good links between these informal systems and the formal health and care system. They need to be seen as part of a wider integration of care around patients. In some areas patients and carers are increasingly being welcomed as partners in the care team in clinical settings. It is also important to break down the barriers between health services, provided by the SNS and other health bodies, and care which may be provided by municipalities, NGOs including *misericórdias* and other voluntary organisations. This report will frequently refer to these links between health and care. For many people, particularly older ones, the two need to be well integrated in order to meet all their needs.

The following Portuguese example shows how one national team is working with parents and partners from all sectors to give their children a good start in life with a focus on nutrition and diet.

PORTUGUESE EXAMPLE

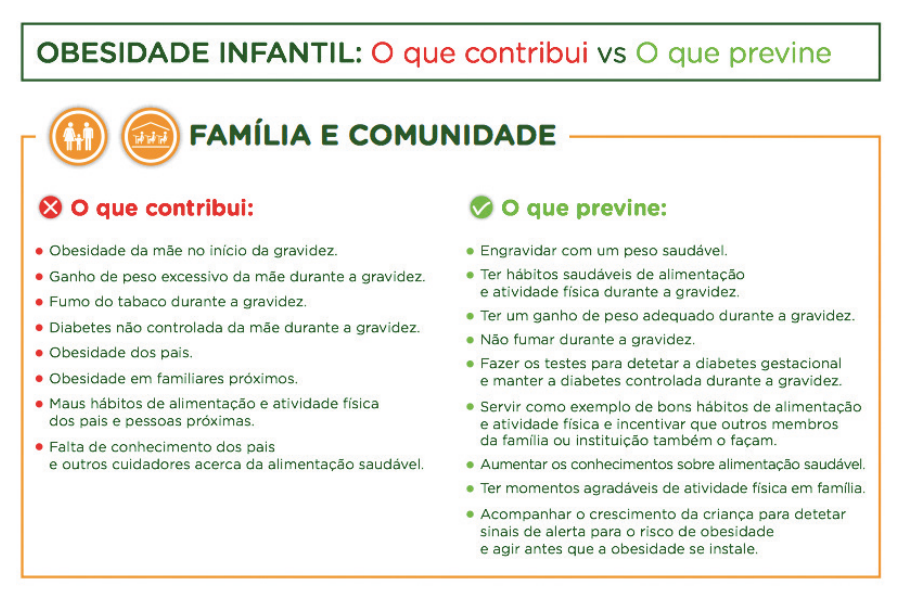
'Papa bem' – healthy children campaign

'Papa bem' (Eat well) aims to support families in the task of promoting the healthy growth of their children. A team at the National School of Public Health, in partnership with the Instituto Nacional de Saúde has developed a set of resources for healthy child development. These include easily accessible online videos, educational leaflets and quizzes on topics such as food diversity, restful sleeping and preventing childhood obesity.

The material has been disseminated among health professionals at primary care units and hospitals such as Hospital Fernando Fonseca and Primary Health Care (ACES) of Sintra. The next step is to run workshops with nursery staff, in collaboration with health professionals working in the same area. These could also include parents acting as local leaders and organize peer groups.

The group is developing pilot projects for implementation and scale up with Lisbon and Sintra municipalities, and the Algarve Regional Health Administration. They aim to conduct an action-research project with these different populations, in different regions of Portugal, to understand the best strategies of implementing a program of promoting healthy lifestyles early in life of – eating behaviors, physical activity, rest and sleep and parenting.

Parents and carers are enthusiastic about the messages and the way they are displayed. There have been around 17,000 visits to the Youtube vídeo "How Breastfeeding works ", and 1200 visits to the "Childhood obesity: Prevention is the best medicine" video.



OBESIDADE INFANTIL: O que contribui vs O que previne

FAMÍLIA E COMUNIDADE

☒ O que contribui:

- Obesidade da mãe no início da gravidez.
- Ganho de peso excessivo da mãe durante a gravidez.
- Fumo do tabaco durante a gravidez.
- Diabetes não controlada da mãe durante a gravidez.
- Obesidade dos pais.
- Obesidade em familiares próximos.
- Maus hábitos de alimentação e atividade física dos pais e pessoas próximas.
- Falta de conhecimento dos pais e outros cuidadores acerca da alimentação saudável.

☑ O que previne:

- Engravidar com um peso saudável.
- Ter hábitos saudáveis de alimentação e atividade física durante a gravidez.
- Ter um ganho de peso adequado durante a gravidez.
- Não fumar durante a gravidez.
- Fazer os testes para detetar a diabetes gestacional e manter a diabetes controlada durante a gravidez.
- Servir como exemplo de bons hábitos de alimentação e atividade física e incentivar que outros membros da família ou instituição também o façam.
- Aumentar os conhecimentos sobre alimentação saudável.
- Ter momentos agradáveis de atividade física em família.
- Acompanhar o crescimento da criança para detetar sinais de alerta para o risco de obesidade e agir antes que a obesidade se instale.

CULTURAL, COMMERCIAL AND ENVIRONMENTAL ISSUES

This report stresses the importance of citizens taking more control and responsibility. However, it recognises that there are cultural, commercial and environmental issues that can present difficulties and barriers to be overcome.

Almost all the Commission's consultations stressed these and related points but they also reflected on how difficult it was to bring about this change in practice. The Commission was told that in Portugal people are generally very passive in their dealings with the health system; they do not feel able to challenge doctors and they make limited use of information sources on health.[8] There were many calls for a change in culture on the part of the public as well as the professionals. The Commission's Working Group 2 argued for a *"shift in the paradigm from a paternalist health system to a system that puts citizens at its centre".* [9]

The Commission also heard that there was in practice very little information available to citizens, for example about the quality of services, and that there was very little transparency about data and about clinical practices. This lack of both data and transparency is a significant problem in Portugal and will be referred to time and again in this report.

Culture cannot be changed in the abstract and will only change through specific actions and as new practices become embedded. This can be very difficult but can also happen surprisingly quickly, as is seen in other areas where, for example, Portuguese people have adopted technology and new practices very quickly – whether it is mobile phone usage and texting or spending through credit cards and on the internet. This chapter will recommend that specific practical actions are taken which will "empower" citizens and start to change this culture.

The difficulties of culture change are not the only problems. There are also global scientific and commercial trends that tend to *dis*-empower people, turning them into consumers who *buy* their health rather than *create* or *co-produce* it. A large part of the problem is simply that science and medicine have become so sophisticated – and health and care systems so complicated – that they tend to overwhelm the layman.

Moreover, there is evidence of an increasing 'medicalisation of everyday life' with more and more human behaviours and needs being seen as requiring complex medical solutions – particularly in relation to obesity and mental health. Commentators have criticised the latest publication of the American Psychiatric Association's classification system for mental disorders for precisely this over-medicalisation of normal behaviours. It lists 750 conditions rather than the 500 in the previous edition, with many entirely new syndromes being identified. Critics argue that it conflates everyday sadness and normal human experiences such as bereavement with major depressive disorder:

"Turning grief and other life stresses into mental disorders represents medical intrusion on personal emotions. It adds unnecessary medication and costs, and distracts attention and resources from those who really need them."[10]

Particularly controversial examples from recent years include depression and alcoholism. It is interesting to note in this context that Portugal has one of the highest levels of anti-depressive medication in Europe.[11] Ben Goldacre also lists social anxiety disorder (a new use for SSRI antidepressant drugs), female sexual dysfunction (a new use for Viagra in women), the widening diagnostic boundaries of "restless leg syndrome", and "night eating syndrome" (another attempt to sell SSRI medication) as "*problems, in a very real sense, but perhaps not necessarily the stuff of pills, and perhaps not all best viewed in reductionist biomedical terms*".[12]

These trends, whilst they obviously suit profit making pharmaceutical and health product companies, threaten the financial viability of the whole system. Very often this trend of medicalization is supported and reinforced by the media and by public attitudes. It is easier to purchase a cure-all treatment than to act to change the factors that make up a "*complex nexus of interlocking social and political issues including work life, employment status, social stability, family support, housing, smoking, drugs, and possibly diet that cause ill health in today's societies.*"[12]

Medicine used to be simple, ineffective, and relatively safe. It is now complex, effective, and potentially dangerous.

These powerful forces and organisations frame the debate as being about services, technology and consumerism and cast citizens as passive consumers. There are also powerful commercial forces at play here and there is a need to limit the power of commercial organisations and health professionals to maximise their economic leverage. As tasks become the province of professionals, patients and citizens are disempowered and have to find new funds to purchase these new commodities. Moreover, it is generally the professionals who dictate the terms: deciding what remedies are needed and charging for supplying them. Safeguards are needed for the public to be confident of sorting out the effective from the useless.

It is also, crucially, about personal risks. As Professor Sir Cyril Chantler has said:

"*Medicine used to be simple, ineffective, and relatively safe. It is now complex, effective, and potentially dangerous. The mystical authority of the doctor used to be essential for practice. Now we need to be open and work in partnership with our colleagues in health care and with our patients."*[13]

Patients and citizens need to be very confident that they understand the risks and either refuse or consent to them. The health professions have produced and continue to produce extraordinary benefits for the population. This has, however, given them enormous power which can prevent citizens and patients form taking more responsibility for their own health.

Figure 3 summarises some of the factors that can *dis*-empower citizens.

Figure 3 · **Factors that can *dis*-empower citizens**

FACTORS THAT CAN DISEMPOWER CITIZENS:

- Cultural habits and expectations
- Lack of transparency and access to information
- The *medicalisation* of everyday life
- The complexity of science and medicine
- Commercial pressures to "sell" treatments and medical technologies
- Professional power

The approach to medicine taken in the last 100 years or more, as we have increasingly given up our control to the professionals, has been one of seeking safeguards from the State through regulation and scrutiny and through placing trust in professionals, their Hippocratic Oath and their social mission. This approach is no longer sufficient by itself, but requires greater transparency and the more active participation of citizens and patients in the governance of health and care systems and in determining their priorities.

Many people – both health professionals and patients' representatives – told the Commission that there needs to be a move away from the traditional paternalism of the health professionals and the health system to a more equal relationship. This will need to be supported by changes in professional education and academic curricula, but it will also require higher levels of health literacy for all citizens, with health education starting early in children's lives.

This new approach will undoubtedly attract resistance from some health professionals, who have been educated and trained for a different environment and may perceive it as a threat to their position and authority. Others, however, will see this as a very positive development recognising the potential that will come from better informed citizens willing and able to play a greater part in their own health care.

THE HEALTH OF PORTUGUESE CITIZENS

These developments in thinking about the roles of citizens take place against a changing pattern of health in the population. Portugal, in common with other countries around the world, is experiencing a great increase in long-term chronic conditions and needs to change both its approach to people with such conditions – supporting them in employment, for example – as well as its health and care services.

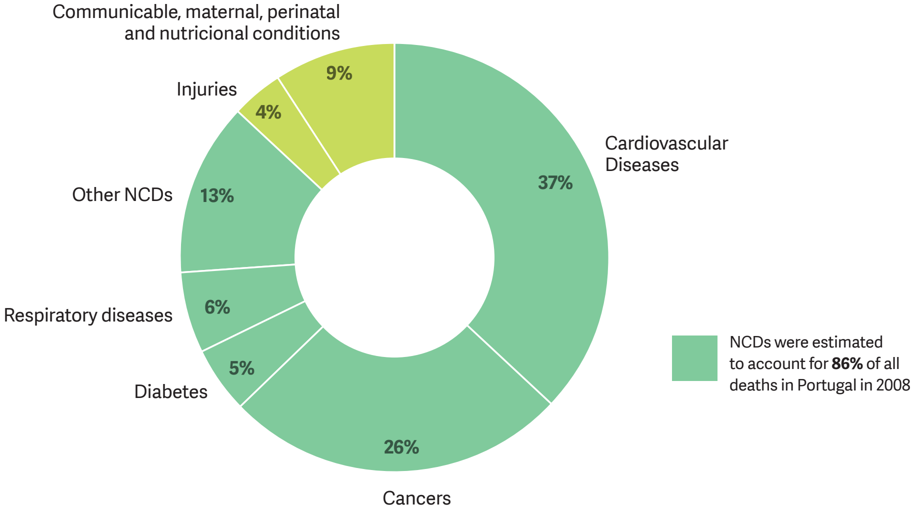
The Portuguese people have seen significant improvements in their health over recent years, with life expectancy approaching the European average and the excellent improvements in child health. These improvements are attributed by the European Observatory to "*improved access to an expanding health network, continued political commitment, and economic growth, which led to improved living standards and increasing investment in healthcare.*" [14]

There are, however, areas of concern particularly in deaths from avoidable causes, male life expectancy, disability-adjusted life expectancy and increasing problems of alcohol and obesity. There are also regional differences with rural areas, which are less affluent and less well served by health services, having poorer health outcomes.

Portugal has not done as well on measures of well-being.[15] It is also believed to have the highest proportion of people living in absolute poverty amongst the EU15 countries.[16,17] Where this is combined with geographical isolation, as in parts of the Southern Region of Alentejo or in Trás-os-Montes, health problems can be particularly severe. Targeted action in recent years has started to close this gap to some extent. These inequalities in access to services and health outcomes are not, however, limited to the rural areas and there is evidence, for example, that illegal immigrants face particular problems despite their rights of access.[18]

The country has an ageing population and its numbers may fall in the future due to a low birth rate, and thereby increase the ratio of dependent people to those of working age. Its patterns of disease are broadly similar to other Western European countries which are also experiencing ageing of the population and seeing increases in long-term conditions or chronic diseases. In 2011 more than 70% of deaths in Portugal were due to chronic diseases, in particular deaths from cardiovascular disease, cancer, respiratory illnesses and diabetes.[19] It is estimated that 5.4 million people in Portugal have one or more chronic diseases.[20] This is shown visually in Figure 4.

Figure 4 · **Deaths in Portugal in 2011**



🟩 NCDs were estimated to account for **86%** of all deaths in Portugal in 2008

Source: WHO, Noncommunicable diseases: Country risk profiles 2011.

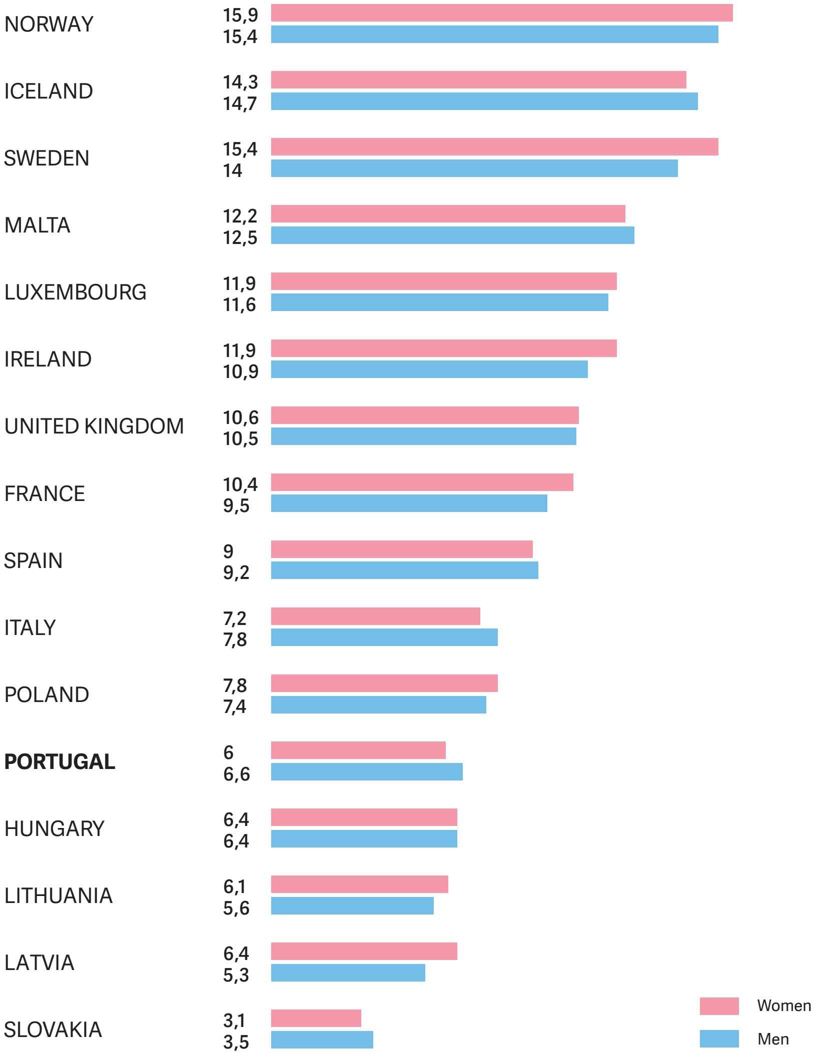
There are, however, a number of distinctive features within this overall pattern. There is a large difference in life expectancy between men and women: 74.9 years as opposed 81.4 in 2008. Men have higher mortality from cerebrovascular disease and malignant neoplasms. There is also much higher mortality amongst men as a result of traffic accidents, with Portugal having the highest level in the EU15.

There are also high levels of diabetes, stroke and HIV/AIDS compared to other Western European countries, with diabetes in particular growing rapidly. More generally, there are high levels of deaths of both men and women from conditions amenable to health care (these are conditions where medical interventions are proven to have an impact – such as reductions in strokes resulting from specific actions and treatments). A 2008 study of 19 high-income countries found that Portugal had the 3rd highest rate of such deaths in 1997-1998 and the 2nd highest in 2002-2003.[21] While the decentralisation of mental health services in Portugal has had a notable impact, a recent report has found that these services continue to suffer from serious deficiencies in terms of accessibility, equity and quality of care.[22] Mental health is one of the Ministry's national priorities, and a National Mental Health Plan (2007-2016) has been established.

This pattern of disease and mortality is reflected in studies which show that Portugal has lower disability-adjusted life expectation (DALE) than the EU15 average – in other words, people suffer more disability at an earlier stage in life and live for a longer period of their life in ill health. The following table from the European Commission shows that Portuguese men and women only have on average 6 and 6.6 years of healthy life after 65 whilst Norwegians have 15.9 and 15.4 respectively. This enormous difference as one of the key challenges which Portugal faces and must be addressed both to improve health and to reduce health expenditure.

The reduction in long-term chronic diseases, their better management and an increase in the length of healthy lives are central to all the actions proposed in this report.

Figure 5 · **Healthy life years after 65**[23]



The position on child health is generally more positive with the indicators of child health near the European average, and infant mortality below (better than) the European average in 2008.[15] A study is currently underway to identify factors contributing to this progress in infant mortality.[24] There are, however, high levels of childhood obesity and Portugal fares relatively poorly on measures of children's well-being, both of which will be discussed in the next chapter.

Table 1 shows how maternal and child health indicators have improved over 40 years. It reveals the very high level of maternal mortality in 1970 and the progress made since, and also shows that the fertility rate halved over this period.

Table 1 • **Maternal and child health indicators, 1970–2009 (selected years)**

	1970	1980	1990	2000	2009
Perinatal mortality rate (per 1000 live births) a	-	23.8	12.4	6.4	4.6
Neonatal mortality rate (per 1000 live births) a	-	15.4	6.9	3.4	2.5
Fertility index b	3.0	2.3	1.6	1.6	1.4
Maternal death (per 100,000 live births) c	73.4	19.0	10.3	2.5	3.8
Adolescent pregnancy rates (age<20, per 100 live births) b	-	-	-	-	4.2

Sources: a INE, 2009g; b INE, 2009a; c INE, 2009f, 2009g.[15]

Many of the conditions discussed here are associated with social conditions and behaviour as well as with ageing. Successive Governments have recognised these problems and implemented public health measures and developed the public health service. Tackling these issues is becoming increasingly important, but it is by no means a straightforward task. The economic growth that the European Observatory Report credits with contributing to the health improvement has gone into reverse. Whilst smoking has declined amongst adults, it has risen in young people. Alcohol use and obesity are both increasing in the population as a whole. Portugal had very high levels of illegal drug usage in the 1980s and 1990s, and the highest rate of drug-related AIDS deaths in Europe. It became the first country to decriminalise drug taking in 2001, treating it as a public health issue. The position has subsequently improved with serious drug use reduced and drug-related deaths and infectious diseases both down markedly.[25]

LONG-TERM CONDITIONS OR CHRONIC DISEASES

The biggest issue affecting Portugal is the growth in long-term conditions and chronic diseases. These diseases tend to need treatment and add costs throughout the system. Heart disease may require surgery, rehabilitation and continuing medication. Diabetes can lead to multiple complications. Moreover, many elderly people have more than one such disease and their needs multiply accordingly. Whilst the analysis has not been done for Portugal, figures for other Western countries suggest that around 5% of patients use about 40% of health care resources and 10% use more than half.[26] Almost all these patients are people with chronic diseases – in the UK for example, 70 percent of total health and social care expenditure is accounted for by the treatment and care of people suffering from long-term conditions.[27]

Chapter 5, which deals with health and care services, describes how many European countries have developed chronic disease management models to deal with patients with different levels of need from the healthy – who need to avoid disease – to the most complex patients with multiple co-morbidities. Prevention of disease and self-care play enormous parts in these strategies and contribute to both quality improvement and cost reduction.

Diabetes has a particular impact in Portugal which has both the highest prevalence in Europe at around 14% and is estimated to cost the country around 0.8% of GDP, with some estimates suggesting it is as much as 1%.[28] Portugal has the world's oldest Diabetes Patients Association which is very active, offers services to the public and keeps the best statistical records and data relating to any disease in Portugal.

Diabetes is important because of the high prevalence and costs but also because there is a high rate of co-morbidity with other diseases. People with diabetes are at a greater risk of developing cardiovascular diseases such as heart attack and stroke if the disease is left undiagnosed or poorly controlled. They also have elevated risks for sight loss, foot and leg amputation due to damage to the nerves and blood vessels, and renal failure requiring dialysis or transplantation.[29] Additionally, the risk factors for diabetes are also factors in other chronic diseases such as cardio-vascular disease. Health policies targeted at reducing the prevalence of diabetes through action across sectors and support for healthy behaviour should also have positive impacts on a far wider range of people suffering from other conditions. This issue will be picked up in Chapter 9 where the report proposes three *Gulbenkian Challenges*.

> Diabetes has a particular impact in Portugal which has both the highest prevalence in Europe (…)

"THE CITIZEN IS AT THE CENTRE OF THE HEALTH SYSTEM"

The Commission heard repeatedly from patients' groups, the Working Groups and other stakeholders that people need to become more engaged in their own health, more empowered to make and share in decisions about their care and treatment, and have a greater influence in health policy-making at institutional, local and national levels. This is national policy in Portugal where the National Health Plan 2012-2016 states very clearly that:

"The citizen is the centre of the Health System, which means that the Health System should be organised with the mission to respond to the citizen's needs, satisfaction and legitimate expectations as an individual and as part of a community, and in his/her various roles: active and healthy, ill, service user, consumer, caregiver, family member and community member." [30]

"Empowering patients means providing them with the opportunities and the environment to develop the skills, confidence and knowledge to move from being a passive recipient of care to an active partner in their health care."

Many different definitions and words are used for action by individuals and groups – *empowering, engaging, involving* or, as the Americans say, *patient activation*. The Commission and its Working Groups have not found any particularly satisfactory language and will generally write about actions by *the individual* or *citizens*, depending on context; and only refer to *patients* specifically when this is the only sensible thing to or in quoting others. The European Network on Patient Empowerment (ENOPE) provides a very useful overview of this whole field:

"Empowering patients means providing them with the opportunities and the environment to develop the skills, confidence and knowledge to move from being a passive recipient of care to an active partner in their health care. Strengthening health literacy, protecting and promoting patient's rights, and ensuring participation of patients and citizens in decision-making processes and providing self-management support are all ways to achieve this." [31]

"The benefits of this approach are numerous for patients, for healthcare professional and health systems. However, for this to occur it needs the joint action of stakeholders from the public sector, civil society organisations, professional groups and academia to support advocacy, resource generation, exchange of experiences, encourage participation, and to build capacity in communities." [31]

Common sense and research alike reveal that patient participation and citizen engagement is needed for many treatments to work effectively. This is shown in examples as different as diabetes, where self-monitoring and self-care has to be the norm, or vaccinations programmes where professionals often have to persuade citizens that the vaccines are safe and in their and their families' interests.

BENEFITS

There is now a growing body of research and evidence on the benefits of action by patients. A recent British Medical Journal study on patient empowerment showed that the degree to which patients are involved in their care makes a major difference to both the quality and cost of their treatment. It concluded that: "*interventions to better inform and involve patients in their care show that, on the whole, they… lead to significant improvements in experience, less dependence on health services, better adherence to treatment and, in some cases, measurable improvements in health outcomes. In short, well-informed, supported and empowered patients serve the interests of individuals and the health system.*" [32,33]

Table 2, which is taken from the study, shows the findings from a systematic review of 132 articles.

Table 2 · **Summarised findings of systematic reviews on effectiveness of strategies to inform, educate and involve patients in their treatment**[32]

Topic	Total number of reviews found	Effects on patients' knowledge	Effects on patients' experience	Effects on use of health services	Effects on health behaviour and health status
Improving health literacy	25	Reported in 13 reviews: 10 positive, 2 mixed, 1 negative	Reported in 16 reviews: 10 positive, 5 mixed, 1 negative	Reported in 14 reviews: 9 positive, 3 mixed, 2 negative	Reported in 13 reviews: 4 positive, 6 mixed, 3 negative
Improving clinical decision-making	22	Reported in 10 reviews: 8 positive, 2 mixed	Reported in 19 reviews: 12 positive, 6 mixed, 1 negative	Reported in 10 reviews: 6 positive, 4 mixed	Reported in 8 reviews: 2 positive, 1 mixed, 5 negative
Improving self-care and self-management of chronic disease	67	Reported in 19 reviews: all positive	Reported in 40 reviews: 24 positive, 11 mixed, 5 negative	Reported in 25 reviews: 14 positive, 9 mixed, 2 negative	Reported in 50 reviews: 39 positive, 15 mixed, 6 negative
Improving patient safety	18	Reported in 4 reviews: all positive	Reported in 1 review: positive	Reported in 3 reviews: 2 positive, 1 negative	Reported in 17 reviews: 8 positive, 9 mixed

One recent study brought home very clearly the relationship between "activated" patients and costs of treatment. It showed that patients with lower activation scores cost up to 21% more as shown in Table 3.

Table 3 · **Relationship between patient activation level and costs of treatment**[34]

2010 patient activation level	Predicted per capita billed costs ($)	Ratio of predicted costs relative to level 4 Patient Activation Measure (PAM)
Level 1 *(lowest)*	966	1.21
Level 2	840	1.05
Level 3	783	0.97
Level 4 *(highest)*	799	1.00

Tables 2 and 3 show a generally positive picture of benefits; however, more research is required particularly about how citizen engagement is organised and delivered across a whole health system. A recent report from the UK's All Party Parliamentary Group on Global Health identified difficulties in being precise about all the benefits of patient empowerment:

"First, it is a difficult concept to quantify and compare, meaning it is hard to say clearly who is doing it better than others and how this has been achieved.[35] *Second, research evidence on patient empowerment, while much strengthened over recent years, still contains important gaps – particularly around the economic effects of large-scale initiatives.*[36] *Third are practical barriers, most importantly the limited time that health professionals have to spend on each patient and a concern that empowered patients will be more demanding, rather than more independent.*[37]

Perhaps the most powerful barrier of all, however, is that many providers genuinely believe this is something they already do. A strong consensus on the importance of patient empowerment has not translated into a strong movement for change. This is despite the fact that only half of English patients in hospital say they are involved in decisions about their care as much as they would like – a figure that has shown no improvement over the last decade.[38] *Professionals also have a tendency to assume what a patient's preferences are, rather than ask, and are often poor at communicating the risks and benefits of different options."*[39,40]

Against this background – of recognising the considerable potential benefits whilst acknowledging the development that is needed – this chapter continues by considering in turn five different groups of actions: self-care, shared decision-making, making choices, patients as experts and health education and literacy. It concludes with a discussion about citizen participation in policy-making and planning. This leads on to the discussions of governance and the role of society in the next chapter.

SELF-CARE – *"THE MANAGEMENT CENTRE OF THEIR OWN LIVES"*

Much of self-care is common sense, whether tackling minor ailments, colds or flu. In some cases patients have to act over the very long-term, taking regular medication or injecting themselves with insulin when necessary. Many problems are, of course, self-limiting and require no action beyond rest and recuperation. People generally understand their bodies better than anybody else and parents are the experts on their children.

Working Group 2 put this neatly in referring to individuals as "*the management centre of their own lives and illnesses*".[9] It continues:

"Self-management of individual health, as in the case of chronic disease, is nowadays an important factor to emancipate and empower citizens and patients to better maintain, or even improve, their quality of life. As a result, one clearly observes benefits and gains for health and an increasingly sustainable health system". [9]

Promoting self-care is not new. A 1997 WHO report lists illnesses and situations where self-management education should become a fundamental part of long-term treatment, in other words a treatment that is more effective and presents better quality.[41,42] Working Group 3 in its report on staffing argues that there needs to be a Portuguese strategy for self-care to recognise and promote this alongside the care and treatment provided by professionals.

People generally understand their bodies better than anybody else and parents are the experts on their children.

Whilst the concept itself may not be new, there are new applications which are often enabled by new technologies. Many people monitor their own health with electronic devices, which help identify the indications when they should seek professional help. In Jonköping in Sweden, the professionals and patients have taken this further in the dialysis unit where 60% of patients now self-dialyse in the hospital, connecting themselves to the machines and monitoring progress.

The big advantage for them is that they can come and go as they please, using a swipe card to enter the unit, and dialyse at any time of day or night. It also improves quality – with no risk of cross-infection – and saves staff time and costs. Any patient can choose to be trained to do their own dialysis and numbers are increasing all the time.

SHARED DECISIONS AND SHARED CARE – *WHAT MATTERS TO YOU?*

Some of what has already been discussed in this chapter can be described as shared care with both clinician and individual playing their part. In reality, much of care outside hospital is shared in the sense that the clinician diagnoses, mostly with help from the individual, and prescribes whilst the individual delivers it, most often by taking a course of medicine. Evidence from other countries, however, suggests that this shared care fails in a quarter to a third of cases with people not following the course of treatment as advised. [43] Whilst no comparable data is available for Portugal, there is little reason to suppose that the position is very different in Portugal.

Shared decision-making, on the other hand is when an individual and health professional discuss the person's health and treatment options, making a choice together. Health professionals give people information about all the treatment options for the health problem, based on the person's medical history and test results. Individuals give professionals information on their life and experiences of illness and treatment. This process helps people "own" their treatment and increases the likelihood that they follow the treatment through fully and accurately.

Shared decision-making has been very well described by Maureen Bisognano, President of the Institute for Healthcare Improvement. The first question the clinician asks may well be "*What's the matter with you?*" but the second question she says should be "*What matters to you?"* This second question is important in very many situations but is particularly so with most long-term conditions where there are multiple questions about which symptoms are most distressing to the individual and which they most want to control.

This is an area of enormous development globally. Parkinson's disease is a prime example of a condition where there are multiple choices and the Dutch Professor Bas Bloem has developed ParkinsonNet as a shared network for patients and professionals alike where they can communicate, learn and share in decision-making. It is discussed in more detail in Chapter 5 as a leading edge example of what future specialist services may look like. There are different ways of doing this. The following three international examples illustrate in turn: a country wide programme for supporting people to ask the right questions and seek the right information; a hospital that has developed a programme for its patients and clinicians; and a country programme to develop decision-making aides nationally with accompanying changes in policy and culture.

INTERNATIONAL EXAMPLES

Just Ask Campaign (DENMARK)

The Danish Society for Patient Safety, in partnership with TrygFonden, has created a variety of initiatives aimed at engaging patients and their families. The Patient Handbook, for example, is a written guide to hospital care that is designed to facilitate patient and family involvement. An estimated 10 percent of all households in Denmark have a copy of the handbook. The Society has also transformed the handbook into question prompts for patients to ask their providers (Just Ask) online, on cell phones and in a paper format. The site allows patients to choose specific questions, add their own, and make suggestions for others to use, and then print out the list of their questions. A study shows that 86 percent of the citizens that have received and used Just Ask in their contact with healthcare providers had an improved dialogue and asked more questions.

The Danish Society for Patient Safety also uses innovative community outreach strategies to initiate conversations with people about how to be more effective partners in their healthcare. Distribution channels for these materials include healthcare providers, patient organizations, hairdressers, media, unions, and businesses.

Scaling Up Shared Decision-Making (USA)

The Health Decision Sciences Centre at Massachusetts General Hospital is seeking to speed the adoption of patient decision aids – evidence based tools designed to inform patients about the risks and benefits of various treatment options and help them come to a "shared decision" with their medical team. A streamlined process has been developed whereby doctors in primary and secondary care get hands-on training with 35 decision aids for common conditions, which they can access through the patient's electronic medical record. The clinician is then able to 'prescribe' an appropriate information tool for the patient before any important decision. This is then noted on the patient's medical record for future follow-up. A training programme is delivered to clinicians to teach them about the benefits of the decision aids and how to use them, in order to try and normalise their use.

The Centre works with 15 primary care practices (covering 200,000 people) and 120 hospital doctors per year. 16,000 of the SDM (Shared Decision-Making) prescriptions have been ordered to date, with initial results from an evaluation showing strong take-up and increased patient satisfaction.

NHS England – shared decision-making aides

The UK programme promotes patient-centered care, increases patient choice, autonomy and involvement in clinical decision-making, and has three distinct aims:

1. **Developing tools which support shared decision-making**. Patient Decision Aids (PDAs) are information resources that help people make decisions about difficult healthcare options. 36 of these have been created to help patients understand and consider the pros and cons of possible treatment options and to encourage communication between them and their healthcare professionals. These are available online and in paper format. Healthcare advisors, all of whom are fully qualified nurses with at least 10 years of experience, are being trained to offer telephone support, developing patients’ confidence and skills in using the tools to deliberate their options.

2. **Embedding shared decision-making in NHS systems and processes**. Making SDM a reality for patients can only be achieved if it is systematically streamlined into routine NHS processes, steering clear of lengthy bureaucratic processes. Integrating shared decision-making becomes an integral part of the patient and clinician pathway. The PDAs need to be easily accessible on NHS platforms. SDM is being integrated into policies, commissioning systems and consent procedures.

3. **Creating a receptive culture for shared decision-making.** The biggest challenge to embedding shared decision-making in routine NHS care is to create a nationwide paradigm shift so patients expect to be routinely involved in decisions about their care. This requires a change in the current patient-clinician dynamic so that clinicians work with patients to encourage and respond to their greater involvement and patients take a stronger interest in being involved. A training and education programme is being developed for providers, including nurses, GPs, consultants and NHS managers, as well as commissioners. Undergraduate and postgraduate medical training is being developed on enhanced communication skills and shared decision-making.

CHOICES

People exercise choice in health and health care in a number of different ways. Most frequently, as we have seen, they are about choices of treatment and of behaviour or lifestyle. They also choose how to access the SNS, with many choosing to go to hospitals rather than to primary care. They can also choose to bypass the public health system, using the private sector or alternative therapies. As will be seen later in the discussion of services and finances, about a third of all expenditure is paid directly by the individual "out-of-pocket" as a result of their choosing to use private services.

There are as yet no substantial studies of the effects of freedom to choose hospitals in Portugal. Studies in other countries show that people tend to be most interested in choices of treatment rather than choices of hospital or location, particularly in rural areas where choices are limited, and that relatively few people exercise their choice to go anywhere other than a local facility. However, there is evidence that the prospect of choice – and the competition it involves – does influence provider behaviour as they try to make themselves attractive choices for people. We return to the subject of competition in Chapter 7 where we argue that it can be useful in some cases, most notably in diagnostic procedures and elective surgery, but that it fragments and interrupts continuity of care in other cases and should not be used.

Studies in other countries show that people tend to be most interested in choices of treatment rather than choices of hospital or location, particularly in rural areas where choices are limited (…).

The Commission believes that citizens should have information about different services and networks and the power to choose which to use. Crucially, they should also be involved in determining what choices they have – what choices matter to them. The evidence here suggests that their preference is for greater choice and decisions about treatment in the discussion with clinicians. At the same time, the Ministry should continue to evaluate the evidence on choices coming from other countries and react accordingly.

One area of choice that is growing fast, particularly in England, is the practice of giving long-term chronically disabled people their own budgets for their care. Personal budgets and direct payments have been used in social care in England for more than 10 years. They aim to increase service user's choice by giving them control of money that would be used to fund their care and allowing them to decide how this should be spent to meet their needs. Over 40% of social care service users in England now have personal budgets or direct payments, and they are now being rolled out to those eligible for NHS continuing health care.

Whilst the Commission would not advocate the immediate adoption of this policy in Portugal, considering the other urgent priorities that the country is facing, developments externally should be monitored so as to understand how this can be done most effectively, mitigating the risks of poor expenditure and maximising the benefits achieved. This is likely to become a very important policy area internationally over the next few years.

EXPERT PATIENTS

People, particularly those with long-term conditions, are most often the experts on their own health. They may not have the technical expertise but many know when something is not right and can often tell when an acute episode is coming. More generally, we can consider expert patients as people who "*are confident and in control of their lives and their illness, who manage their condition in partnership with health professionals, are realistic about how their condition affects them and use their skills and knowledge to lead a full life.*"[44]

The Chronic Disease Self-Management Program was established at Stanford in the United States in the 1990s as a research programme and was subsequently developed into a mainstream activity. It consists of a series of workshops in community settings, and covers subjects such as techniques to deal with problems like frustration, fatigue, pain and isolation; appropriate exercise; communicating effectively with family, friends, and health professionals; nutrition; decision-making; and how to evaluate new treatments.[45] Subjects who took part in the Program demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue and disability. They spent fewer days in the hospital, and there was also a trend toward fewer outpatient visits and hospitalisations.

(…) we can consider expert patients as people who *"are confident and in control of their lives and their illness, who manage their condition in partnership with health professionals, are realistic about how their condition affects them and use their skills and knowledge to lead a full life".*

The Expert Patients Programme in the UK, built on the experience from Stanford, was established as a central element of chronic disease management policy in the UK. The program aims to deliver self-management support and improve the quality of life of people with long-term conditions by developing skills and improving people's confidence and motivation to take more effective control over their lives and illnesses.[46] Research suggests that the benefits of self-management include reducing the severity of symptoms, significantly decreasing pain, and improving activity levels and life satisfaction.[46] One survey of people that had taken part in an Expert Patients Programme found that they felt more confident, better prepared for appointments with healthcare professionals, and made fewer visits to their GP and emergency departments.[44]

Patients can also be used as experts in the education and training of health workers and carers. A report by The Health Foundation[47] on involving patients in healthcare professionals' education found that across the UK, the involvement of people who are patients, carers and service users is well established in certain sectors of health and social care professional education, notably social care and non-psychiatric mental health. In other areas such as medical education, and continuing professional development, comprehensive involvement is uncommon. Generally patient/user involvement in health professional education is low on the agenda of influential leaders in health professional education, either at the institutional or national level.[47]

The report also notes that there is strong evidence that patient/user involvement has short-term benefits for all involved, including learners, educators, institutions and patient/users, across a wide range of domains, such as knowledge, skills, attitudes and behaviours.

Patients can also be used as experts in the education and training of health workers and carers.

HEALTH LITERACY AND EDUCATION

Clearly health literacy and education are the foundation for progress in enabling citizens to be much more active in health. The Commission's Working Group 2, on Citizens and the SNS, has deliberated extensively on this and provided clear advice to the Commission.

The Working Group took as its starting point the Institute of Medicine definition of health literacy as:

> *"the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions".*[48] *Being health literate means that someone has basic health knowledge; is able to read, understand and weigh up health information; is able to analyse risks and make calculations; and is capable of verbally communicating and interacting with health professionals.*

The Working Group 2 reported that:

> *"Low levels of health literacy have a negative impact on patients' interactions within the health care setting, patients' navigation through the health care system, and the quality of communications between patient and health professionals, all of which can ultimately contribute to poor health outcomes. Some studies have reported patients' inability to understand directions for taking medication on an empty stomach or standard informed consent forms in public hospitals.*[49]
>
> *It is known that low health literacy individuals have less knowledge of their health conditions and treatment regimens, have poorer self-management skills and do not engage with preventive measures, such as vaccinations and screenings. Limited literacy is also related with higher healthcare costs, increased used of healthcare services and higher rates of hospitalization.*[50] *A survey showed that low literacy is found in 45% of people in Europe, mainly in individuals with lower levels of education, lower social status, lower incomes and older people (European Health Literacy Group, 2012). However, even people with advanced literacy skills may find it difficult to obtain and understand health information. Individuals may experience a sense of shame when they do not understand health information, even in the context of interactions with health professionals. As a result, they may hide their difficulties and rarely ask for help".*

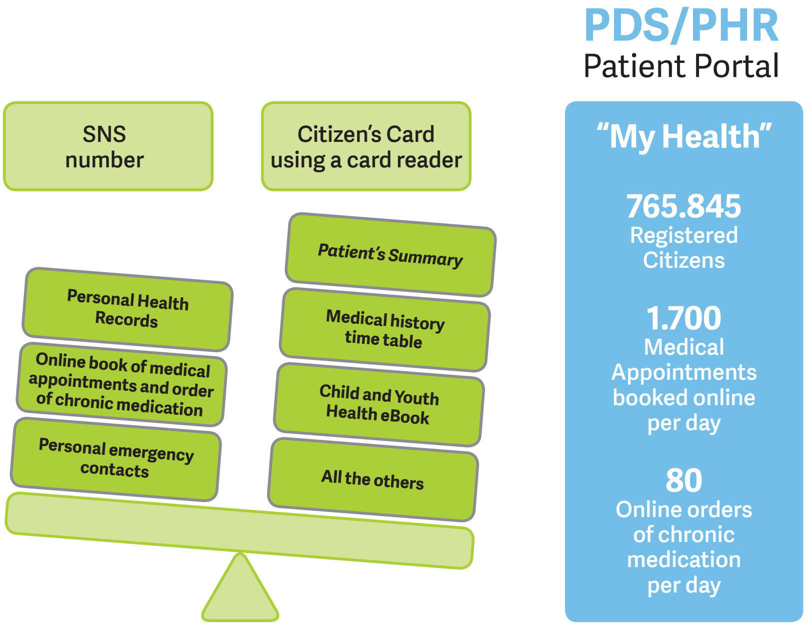
Working Group 2 argues that:

> *"the implementation of a national policy for the promotion of health literacy should be a top priority to improve the health status in Portugal. This should encompass an inter-sectoral strategy involving all society sectors, at the national, regional and local level, within the philosophy of "health in all policies". This strategy should emerge from the measurement of citizens' health literacy, through adopting evidence-based methodologies".*

The Working Group also stressed the importance of access to good quality information using all the new technology and channels that are now available. Its proposals include the development of a Health Citizen's Guide for navigation in the healthcare system, which has some similarities to the Danish "Just Ask" model described earlier. Its full proposals in this area cover websites, mHealth, a health store, and telephone, TV and media channels. They are summarised in Appendix 5.

Portugal already has an effective Patient Portal, illustrated in Figure 6, which allows people to log on to find some information about themselves and about health services.[51] It could be extended considerably to become the authoritative source for almost all their health information needs. At the same time, development of an Electronic Health Record, which is discussed in Chapter 4, will allow people greater control over their own health care.

Figure 6 · **The Patient Portal**



The following Portuguese examples illustrate, first, how clinicians can engage in education as part of their normal roles and secondly, how the *Português Claro* Plain Language campaign can help to provide information that is understandable by a higher proportion of the population.

Unidade de Saúde Familiar Alpha Mouro

This local health centre is in a poorer neighbourhood on the outskirts of Lisbon which serves a diverse population of both Portuguese and migrant families.

The centre is an excellent example of inter-professional team-work, with nurses and doctors working closely and cooperatively. All health professionals are given their own office and all wear white coats – little differentiation is made. Nurses are given specialist training on wound treatment and diabetes, and are responsible for triage, care and management of chronic patients, child and reproductive health.

The centre is also working to improve health literacy among its users. Staff have taken it upon themselves to produce educational material about health issues and services. They also endeavor to teach patients more about their conditions during consultations.

Registered patients will almost always come to the centre before going to the emergency ward or hospital, and report a positive relationship with staff.

Português Claro – plain language for Portuguese citizens

Português Claro introduced plain language in Portugal and has been helping Portuguese companies and government agencies communicate clearly since 2007. They work to improve information design in public documents as a way of helping citizens make informed choices about their health, education, welfare, and civil rights.

The general levels of literacy in Portugal are still low – a significant number of the population still cannot read or write at all, and a majority have difficulty understanding technical or complex language, such as instructions for taking medication, diagnostic test results or legal documents.

CITIZEN PARTICIPATION IN POLICY-MAKING AND PLANNING

Citizen participation in health policy-making is increasingly prioritised by international organisations such as the World Health Organization[52] and national governments around the world, with the aim to give the public agency and responsibility for their own health.[53] The specific concepts of citizen empowerment and participation in social and health policy are closely tied to democratic rights, and historical and modern understandings of citizenship. They address the role of population in the health system in a wider sense, in terms of decision-making, influencing policy processes, community activism, and the rights and responsibilities of citizens in relation to the health and well-being of the whole society.

Forms of citizen empowerment vary between health systems, and are strongly linked to a country's historical political context and democratic institutions. In countries such as Brazil, citizen participation in policy-making is a right, guaranteed by the 1988 Constitution that came about after decades of dictatorship. In the UK, the focus is on patient empowerment at the individual level and to improve service design. A key difference here is that whilst in England there is now a *duty* on health services to involve the public, in Brazil there is a *right* to representation.[54] The recent writing into law of the *Carta dos direitos de acesso aos cuidados de saúde pelos utentes do SNS*[55] in Portugal indicates that the country is following a path where public participation in healthcare decision-making is seen as a citizens' right, and should lead to wider involvement by Portuguese people in health policy-making.

Citizen empowerment for health can be understood in the broadest terms to refer to activity by the public that improves their health and well-being. Community participation and empowerment is, for example, at the centre of the WHO European Healthy Cities Network. Here participation is defined as *"a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change"*.[56]

Citizen empowerment for health can be understood in the broadest terms to refer to activity by the public that improves their health and well-being.

The rights of individuals as citizens are well recognised in Portugal, with the National Health Plan containing many policies about citizens' involvement and also, more recently, with the updating of the *Carta dos direitos de acesso aos cuidados de saúde pelos utentes do SNS*. This Charter contains a wide range of rights and responsibilities for both the state and the individual.

The rights of citizens to participate in decision-making in health are also guaranteed by the Law on Health from 1990[57] which, is designed to ensure:

- the participation of individuals and the community in defining health policy, and in the planning and control of services
- the right to defend their interests through organizations that represent them
- the right to form associations for the promotion and protection of health
- the opportunity to influence policy-making at the highest level through the National Health Council

These requirements, however, have not yet been fully met. There is little representation from lay people on health bodies and the National Health Council itself has not yet been formed.

Portugal's policy on citizen participation is amongst the most advanced in the world but its implementation lags behind many countries. The improved governance of health systems has now become seen as one of the key issues that can lead to improvements in health care delivery by a very wide range of policy makers, practitioners and academics. These improvements always involve the need to engage citizens and civil society fully in structures and processes. The WHO report on Governance for Health in the 21st Century points out that "*successful governance for health requires co-production as well as the involvement and cooperation of citizens, consumers and patients. As governance becomes more widely diffused throughout society, working directly with the public can strengthen transparency and accountability.*"[58]

Many countries have implemented changes both in laws and in structures. Citizens' representatives sit on health and hospital boards, professional regulation has been opened up to lay people and "freedom of information" laws are allowing far more public scrutiny of decision-making. These developments are accompanied by greater openness as well as access to high quality data and information.

Many of the people consulted by the Commission reinforced the need for improved information and also stressed the importance of greater transparency and the removal of conflicts of interest. The way the health system is currently structured and the lack of information and openness are a problem in Portugal – and perceived to be so by many stakeholders. Working Group 2 wrote: "*Conflict of interest, the clash between an individual's self-interest and the public interest, is a problem in all health systems. The goal of transparency is to bring conflicts of interest out into the open so that all stakeholders have the same information leading to fairness and the furthering of the public good.*"

The Government has recently set out new regulations for managing potential conflict of interests – in response to these sorts of concerns. Its policies promise better information and greater transparency. There is, however, still a long way to go. Working Group 2 wrote: *"Quality, accountability and transparency are interdependent. Major steps forward have been taken recently in Portugal but more needs to be done, both for citizens and by citizens and doesn't only hinge on the sharing of information: "Simply making information available is not sufficient to achieve transparency. Large amounts of raw information in the public domain may breed opacity rather than transparency."*[59]

The Working Group goes on to make a number of very important recommendations on securing transparency. These are reproduced in Appendix 4. The Commission commends these to the Government as an important addition to the rights enshrined in the citizens' rights charter.

CONCLUSIONS AND RECOMMENDATIONS

There is a very widely shared view in Portugal that citizens need to be much more active in promoting health and improving health services and to make fuller use of their existing rights to do so. The benefits of this are becoming more evident with time. There are, however, difficulties to be overcome.

Portugal has many excellent policies in this area; however, implementation has been patchy and slow – often limited to small scale initiatives which have involved people already interested in change. The real impact will come from implementation across the whole system from the *early adopters* to the *laggards*.[60] Decisive action across government is now needed at scale to give citizens central and influential roles in improving health and the health system and to equip them to be able to do so.

This chapter has drawn heavily on Working Group 2's deliberations and on input from many different stakeholders. Following discussion with the Group and further deliberation, the Commission has decided to make four recommendations here.

The four recommendations in Figure 5 are intended to provide the structures and environment to enable this to happen. The growth of health literacy is fundamental and needs to be undertaken powerfully and at scale. This needs to be supported by citizens owning their own health information as held in official records. At the same time, there need to be improvements in information, transparency and representation of the public on health bodies.

These four recommendations will help to create a new environment and culture within which citizens can really be as the National Health Plan asserts "*the centre of the health system*" and where, as Working Group 2 suggests, they are "*the management centres of their own lives*".

Figure 5 · **Recommendations**

RECOMMENDATIONS

5. **HEALTH LITERACY.** There needs to be a new cross-government national programme for health education and health literacy which will equip citizens in practical terms to stay healthy and, when ill, share in decision-making. This should be very high profile and led by an independent group of Ambassadors, including people from the media and communications, who would report to the Ministers of Health and Education.
6. **OWNERSHIP OF PERSONAL HEALTH INFORMATION.** High priority needs to be given to implementing fully the Electronic Health Record as the essential underpinning of an integrated and high quality service and giving citizens ownership of all the health information held about themselves whether in an electronic form or otherwise.
7. **ACCESS TO INFORMATION.** There needs to be a single authoritative source of information available to citizens, perhaps built on the *Portal da Saúde*, which would cover information about health, disease prevention, and services and their quality. Health organisations should be placed under an obligation to provide an agreed range of data for this purpose and regulators should ensure that citizens have this access.
8. **REPRESENTATION.** The Ministry of Health should appoint lay people, able to represent the perspective of citizens and patients, to the boards of all health bodies where it has the right to make appointments.

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3

Action across society

Modern societies actively market unhealthy lifestyles and modern environments make it difficult to make healthy choices. Action is needed from all sectors of society to improve health as well as from citizens and national and local government.

"Modern" societies actively market unhealthy life styles[1]

This quotation from a WHO report shows how much has to change in order to achieve our vision of a health promoting society which provides a health creating or "salutogenic" environment and actively markets and supports healthy life styles.

This chapter discusses the major changes that are needed across the whole of society in order to achieve significant improvements in the health of the population. These changes involve cross-sectoral approaches to health and are themselves only part of far bigger changes to the reform of the welfare state in Portugal.

HEALTHY SOCIETY

A healthy society of the future would be one where, in line with an understanding of the impact of the different determinants of health:

- Towns, cities and the whole physical environment are designed to promote healthy living; where healthy food is available everywhere; and where pollution and carbon usage are under control and minimised.
- Citizens understand their rights and responsibilities, they contribute to informal networks of care for family, friends and neighbours; and there is greater social cohesion and less exclusion and inequality.
- Municipalities and government departments, private entities and voluntary organisations work together to shared goals; where health and care services are integrated with other social and public services; and where citizens share in the governance of health organisations.

It is a future which in many ways draws on the past when leaders across Europe built their national versions of a welfare state based on "social solidarity". It is a future that is also very connected to the present globally where there is an explosion of interest and creativity in designing new and healthy environments, reducing pollution, developing healthy foods, offering lifestyle advice – and using both bio- and information technology to do so. In countries as far apart as China, the United Arab Emirates and the United States governments and private organisations are commissioning healthy and sustainable cities and living spaces.

In Portugal, too, there is a great deal of interest in healthy cities and communities. The Portuguese Network of Healthy Cities is an association of municipalities whose mission it is to support the dissemination, implementation and development of the Healthy Cities project in the municipalities wishing to prioritise health promotion. The network currently includes 28 cities and towns across Portugal, covering around 25% of the population.

Moreover, the *Future Cities Project* aims to turn Porto into a 'living lab' which will track all different sorts of activity within the city using advanced technologies for data collection through mobile platforms, wireless communication and large-scale information processing. This will provide support for research in areas such as sustainability, mobility, urban planning and information and communication technology. This will be invaluable for health as it will help reveal how the environment affects patterns of behaviour and support the development of health promoting environments in the future.

PORTUGAL TODAY

(…) everything about modern society (…) combines to encourage a sedentary lifestyle.

Today's reality in Portugal is, however, more problematic. Portugal is a modern society subject to all the pressures that led the WHO report to conclude that *"Modern" societies actively market unhealthy life styles.* The simple point being made is that everything about modern society – from fast food, the availability of motorised transport, home based entertainment and building design – combines to encourage a sedentary lifestyle. On the one hand, easy access to alcohol, sugary foods and, until recently, cigarettes, means that it is all too easy to make unhealthy choices in our consumption of goods. On the other hand, low health literacy and confusing and contradictory information makes it difficult to make wise decisions regarding what we eat, drink, how much we exercise, what medicines we take, and whose advice we follow when it comes to treatment.[1] Some of these issues such as health literacy and access to information will be addressed by the recommendations from the last chapter, but other will need a different approach.

Portugal has also been affected by the economic crisis, high rates of unemployment, and severe cuts in public spending. The Memorandum of Understanding between the Portuguese Government and the "troika" (the tripartite committee made up of the European Commission, the European Central Bank and the International Monetary Fund) of May 2011 had more than 50 measures and actions which have or are likely to impact upon healthcare provision. Many more, of course, impact upon the wider determinants of health.[2,3,4]

Government has had to make quick and short term decisions and not had the breathing space to invest time and energy in planning for the longer term. A danger in this is that the welfare state and the implicit social contract of the 70s and 80s is torn up for short term reasons and that nothing substantial is put in its place. Now, as the country emerges into a calmer period, is the time for bold leadership to redesign the system and create a new social contract between citizen and state.

Moreover, there are signs that the strong sense of social cohesion in Portugal immediately after the Carnation Revolution in 1974, with its surge in civic participation,[5] has begun to dissipate. As Portuguese society shifted to democracy in the 1970s, many public institutions adopted systems designed to promote participation and consultation from citizens[5]. Several of Portugal's oldest charitable institutions are still active, including the *misericórdias*, which have an important role in the health sector. However, in recent years there seems to have been a decline in social cohesion and participation in voluntary activity.[6, 7]

In a cohesive society citizens have a high degree of confidence in their governmental institutions and public administration. In Portugal, 43% of people say they trust their political institutions, lower than the OECD average of 56%. High voter turnout is another measure of public trust in government and of citizens' participation in the political process. In the most recent national elections for which data is available, voter turnout in Portugal was 64% of those registered, compared to the OECD average of 73%.[6]

There is a reported sense of disillusionment among poorer parts of the population, who regard the wealthier sections of society as self-interested and exclusive. The recently created *Sistema Nacional de Integridade*, which monitors and campaigns against corruption in Portugal, has drawn attention to the significant use of "cunhas" (connections) to gain work, promotions or favours.[8]

As the acute phase of the economic crisis fades in Europe, it is being replaced by heightened inequalities with sharper differences between those with secure jobs and pensions – and a stake in society – and those without.[9] This particularly affects younger people across the continent who are experiencing very high levels of unemployment. In Portugal many are leaving the country, fearful about the future. Portugal with its ageing population and low birth rate cannot afford this exodus in the long-term and needs to offer its young people a vibrant and prosperous future in the country.

All these things matter to health as well as to the health and cohesiveness of society. There is increasing evidence that social support and community cohesion are beneficial to our well-being in multiple and complex ways. The frequency of our contact with others and the quality of our personal relationships are crucial determinants of our health.[10] Local social organisation plays a major role in promoting healthy behaviours such as physical activity, and exerts some measure of social control over behaviours such as smoking and alcohol abuse.[11]

REDESIGN OF THE SYSTEM – THE CONTRIBUTION OF HEALTH

None of these developments are going to be easy to reverse. They are global trends that affect all developed countries. The OECD in a recent report on reforming the state to promote growth in Portugal makes recommendations for redesign of the welfare state, including the SNS.[12] It describes the state as the key enabling actor in creating an environment conducive to stronger growth and well-being in Portugal, which includes "*not only the State's role in the design, development, implementation and monitoring of reforms, but also its role as regulator and service provider*". Health is only a part of these major social changes; but it can play its part in creating a better future. The Commission's recommendations are all designed to contribute to this wider societal goal. In the last chapter the Commission recommended empowering citizens and patients, creating greater openness and transparency. In this chapter it proposes a focus on cross sectoral action on health and other social goals with changes in governance and the strengthening of public health. In future chapters it will recommend a commitment to quality improvement and to using scientific knowledge and new technologies to the best effect. All these recommendations will help shape a different and more inclusive society.

Portugal, of course has much to build on – it has for the most part an enviable life style and climate and a strong cultural heritage. Moreover, it has previous experience of tackling major social issues in a way that brings the resources of many different parts of society and the population together to achieve common goals.

The following three examples, two from Portugal, show where bold decisions have been made in the past and brought great benefit. The first is the well-known story of how Portugal has reduced childhood and maternal mortality over the years through action across all parts of society. The other two examples are where the health and care system is contributing to shared wider social goals that go well beyond health alone and bring wider benefits to Portugal and Scotland respectively. There are lessons to be learned from all of them.

PORTUGUESE EXAMPLES

Improvements in infant and maternal mortality

Portugal achieved an extraordinary decrease in the infant mortality rate of 94% between 1970 and 2008, better than any other European country and is now amongst Europe's best performers.

A report by Fundação Francisco Manuel dos Santos[13] found that the most significant impacts were a result of the major reforms to maternal and child healthcare by the Comissão Nacional de Saúde Materna e Infantil (CNSMI) in 1989, which involved the reorganization and upgrading of the network provider of care, and the establishment of regional referral networks.

The report also shows that there were a wide range of socio-economic factors, which combined also contributed to the significant improvements in child and maternal life expectancy. These included improvements in female education, literacy and employment; increased government expenditure on health; skilled assistance during and after childbirth; and improvements in sanitation, living conditions and nutrition. These society-wide improvements would have involved a considerable degree of coordination and collaboration between the health, education, environment, housing and other sectors, and proves that a cross-sectoral approach is feasible in Portugal.

The CNSMI was given strong political support, but worked autonomously and with freedom to implement the reforms. The changes were well planned and evidence-based, and were communicated clearly to the public. The evaluation of both the implementation of the reform and of its results was one of the most important aspects of the plan.

This success demonstrates that Portugal is capable of driving through a change long-term where it is well led, well communicated and owned by the population and clinicians.

The decriminalisation of drug usage

In July 2001, Portugal introduced a law which decriminalized the use, possession and acquisition of all types of illicit substances for personal use, which was defined as being up to ten days supply of that substance. Possession has remained prohibited by Portuguese law and criminal penalties are still applied to drug growers, dealers and traffickers.

The main features of these changes were ending the use of penal sanctions for drug possession (previously, offenders had been liable to fines or up to a year in prison), and introducing a system of referral to Commissions for the Dissuasion of Drug Addiction (CDTs), regional panels made up social workers, legal advisors and medical professionals.[14]

The CDTs use targeted responses to drug users, including sanctions such as community service, fines, suspension of professional licences and bans on attending designated places. But their primary aim is to dissuade new drug users and to encourage dependent drug users to enter treatment. Towards this end they determine whether individuals are occasional or dependent drug users and then apply an appropriate sanction. Fines are not used for people who are considered to be dependent on drugs. For these people, the CDT can recommend that the person enters a treatment or education programme instead of receiving a sanction.[15] The law formed part of a strategic approach to drug use which aimed to focus police resources on those people who profit from the drugs trade, while enabling a public health approach to drug users. It developed from a period of reflection and debate, which led to the adoption, in 1999, of a National Strategy for the Fight Against Drugs, which emphasises the principles of humanism, pragmatism and the right of people who have drug problems to receive treatment.

The national strategy has led directly to increases in the scale of treatment and prevention activities in Portugal. It seems that there has been a shift in drug use patterns, with increasing use of cannabis and decreasing use of heroin. The rise in cannabis use is probably less threatening to public health than the levels of heroin use that were recorded prior to 2001. The reductions in drug-related deaths and blood-borne viruses also suggest that there have been public health improvements since 2001.

INTERNATIONAL EXAMPLE

Scotland's Early Years Collaborative[16]

The Scottish government has the ambition to make Scotland the best place in the world to grow up in by improving outcomes, and reducing inequalities, for all babies, children, mothers, fathers and families across Scotland to ensure that all children have the best start in life and are ready to succeed.

By engaging professionals and ordinary citizens from across society – health and social care, education, police, voluntary sector – and working collaboratively, Scotland aims to make significant steps towards a healthier society.

The objectives of the Early Years Collaborative are:

- Deliver tangible improvement in outcomes and reduce inequalities for Scotland's vulnerable children.
- Put Scotland on course to shifting the balance of public services towards early intervention and prevention by 2016.
- Sustain this change to 2018 and beyond.

Its key aims are:

- Positive pregnancies: To ensure that women experience positive pregnancies which result in the birth of more healthy babies as evidenced by a reduction of 15% in the rates of stillbirths (from 4.9 per 1,000 births in 2010 to 4.3 per 1,000 births in 2015) and infant mortality (from 3.7 per 1,000 live births in 2010 to 3.1 per 1,000 live births in 2015).
- 27-30 month reviews: To ensure that 85% of all children within each Community Planning Partnership have reached all of the expected developmental milestones at the time of the child's 27-30 month child health review, by end-2016.
- Successful entry to primary school: To ensure that 90% of all children within each Community Planning Partnership have reached all of the expected developmental milestones at the time the child starts primary school, by end-2017.

THE DETERMINANTS OF HEALTH AND THEIR IMPACT IN PORTUGAL

The practical importance of taking a cross sectoral approach to health is supported by recent advances in knowledge and science that demonstrate that environmental and social factors are major determinants of how healthy a person is and, except in times of acute or prolonged crisis, can have greater beneficial impact than health services themselves. This new understanding has helped move policy makers away from using a purely biomedical model in their search to improve health and prevent disease.

As we noted in the last chapter, a wide range of factors in our social, economic and physical environments, as well as individual characteristics and behaviours determine our health and the health of the wider population. Physical factors such as safe water and clean air, healthy workplaces, safe houses, communities and roads all contribute to good health.[17] The health benefits of access to adequate and nutritious food, healthy dietary patterns, food hygiene and other sanitation measures are strongly established.

Commercial interests also have a big impact on health. Some of these, associated with healthy living, exercise and good nutrition are very beneficial. However, high levels of sugar in foods and soft drinks are particularly damaging, yet sugary foods and drinks are heavily advertised in Portugal and other countries. Earlier research suggested that high consumption of sugar was related to obesity and obesity was related to diabetes. Very recent studies, on the other hand, show a direct and independent link between sugar and diabetes.[18,19] The WHO is currently considering strengthening its guidance on the use of sugar and reducing the recommended maximum levels. This is clearly an area where Government intervention and regulation may be necessary as a health promoting measure.

In the past few decades in particular there has been a growing acceptance of the substantial role that social and interpersonal factors have on our mental and physical health. These have been more complex to identify and research, but work done by Professor Sir Michael Marmot and others on the social determinants of health demonstrates the important role that stress, job satisfaction and self-worth have on both our mental, emotional *and* physical well-being. [20,21] Within countries there are dramatic differences in health that are closely linked with degrees of social disadvantage. The WHO Commission on the Social Determinants of Health found that these avoidable health inequalities arise because of the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness.[22] The conditions in which people live and die are, in turn, shaped by political, social, and economic forces.

At the Gulbenkian conference in February 2014, the then Chief Medical Officer of Scotland, Sir Harry Burns, discussed the work of medical sociologist Aaron

The health benefits of access to adequate and nutritious food, healthy dietary patterns, food hygiene and other sanitation measures are strongly established.

Antonovsky on "salutogenesis", an approach that focuses on the relationship between health, stress and coping.[23] Antonovsky observed that most people experience stress, but that not all have negative health outcomes in response. There are coping resources, such as social support and ego-strength, which help individuals deal with stress. Most importantly, there is a "sense of coherence" – that events in life happen in an orderly and predictable fashion; that we have the skills, resources and support to manage things; and the belief that things in life are interesting and that there is reason for us to care about what happens – which determines whether stress causes us harm.

Burns discussed the relevance of this work for the Scottish population, demonstrating the relationships between cortisol levels (the hormone released when stressed) and grade of employment and time spent in foster care. He suggested that one explanation for the particularly high levels of poor health in areas of Glasgow could be linked to working and living conditions which have damaged social support networks and personal investment in work. There will be similar processes at work in Portugal and other countries.

The big improvements in health in Portugal in the last 40 years have in part come about as a result of improvements in the economy and in society as a whole. They have been accompanied by substantial improvements in educational attainment and the literacy rate: both are now approaching the OECD average, albeit from a very low base. Incomes have grown for individuals as well as for the state as a whole. Housing has also improved with more Portuguese people saying they are satisfied with their current housing situation and living conditions than the OECD average.[6]

However, whilst major advances have been made in education and literacy in Portugal, almost 20% of the population still lives near or below the poverty line.[24] Poverty is very significant as a determinant of health and these figures emphasise the importance of poverty reduction and alleviation in Portugal as a means, amongst other things, of improving the health of the population.

The next few sections examine the interface between social conditions and health as they affect different sectors of the population.

CHILDREN AND YOUNG PEOPLE

There have been, as described above, very substantial improvements in infant mortality in Portugal; however, these improvements have not been replicated in the health of children in later life or in surveys of childhood well-being.[25] Obesity levels in children are amongst the highest in Europe. Encouragingly, the Ministry of Education told the Commission that a recent pilot programme in Oeiras for increasing physical activity in schools had led to improved fitness and to higher educational attainment.[26] The Ministry also told the Commission that schools were experiencing a significant increase in numbers of children with mental health and behavioural problems and drew its attention to the way increases in poverty were impacting on children.

The Ministries of Education and Health have agreed a protocol for joint working to create a national platform for the promotion of healthy and active lifestyles. As yet, this does not appear to have been operationalised but it does offer a useful policy background for joint action. The Commission also noted that there is a *Healthy Schools* programme in Portugal which involves most schools and that a new collection of data was underway from all schools which would provide information that enabled schools and their partners to target problem areas in terms of health and well-being.

There have been (…) very substantial improvements in infant mortality in Portugal; however, these improvements have not been replicated in the health of children in later life or in surveys of childhood well-being

Moving to the older group, there is, as already noted, widespread concern among younger people about their future prospects, particularly with regard to employment. During the last four years the prospects for Portugal's youth have deteriorated profoundly through a combination of escalating unemployment and the continued precariousness of the labour market.[27] After rising to 38.6% in 2012, the youth unemployment rate stands at 35% as of February 2014 – compared to an EU28 level of 22.9% and more than double the OECD average of around 16%.[28]

As a result of this, young people are increasingly seeking work abroad, with many migrating to Northern Europe, and smaller number to Brazil and other Portuguese speaking countries. This pattern of migration in search of work is likely to exacerbate problems in a population where the dependency ratio of children under 14 to the adult working population is swiftly declining.[29]

There is evidence that young women are increasingly putting off having children due to their concerns about maintaining employment and the financial viability of starting a family. Many are choosing to delay or forgo having children due to fears they may lose or be refused work. This is shown in the rising age at which Portuguese women have their first child, as well as the rapidly decreasing birth rate. Just 6,439 new births were registered in June 2012, 19% fewer than the same month the previous year, and the lowest monthly tally for more than 60 years.[30] Portugal is experiencing a rapidly declining birth rate, which has decreased at around 10% over the last couple of years, now standing at around

90,000 births, lower than the 100,000 target to keep the population from shrinking further.[31] Portuguese women's fertility rate currently stands at 1.32, amongst the lowest rates in the world.

A young, healthy workforce is vital for the support of the aging population, both in terms of familial care and to fund a tax-based system for financing health and social services.

OLDER PEOPLE

People across Europe are living longer. However the benefits of longer lives are limited by the fact that for too many people old age brings a high risk of social isolation and poverty, with limited access to affordable, high-quality health and social services.[32] As noted in the last chapter, Portuguese men and women live longer periods of their lives – mainly in their later years – in ill health and with some level of disability. At the same time, there is a proportional increase of the population aged 65 and older in rural communities, with 25% of the elderly population living in the interior.[33] This brings with it the greater chance of isolation and the loss of local services.

Well thought through and cross-governmental public policies are needed to ensure that positive trends can be sustained and the benefits of a longer life can extend to everyone, regardless of where they live or the socio-economic group to which they belong. The Government has invested in health promotion and in a National Network for Integrated Continuous Care (RNCCI), which aims to support people in the community and improve autonomy and social interaction for older people. However, as Chapter 7 which deals with finance demonstrates, Portugal spends far less on long-term care than other western European countries and this will undoubtedly need to remain a priority into the future. Preventing and delaying the onset of ill health in old age will be, as is argued in Chapter 7, an even higher priority for the future.

(…) the benefits of longer lives are limited by the fact that for too many people old age brings a high risk of social isolation and poverty, with limited access to affordable, high-quality health and social services.

Older people should not, of course, be seen as a burden. The Calouste Gulbenkian Foundation's report on ageing and social cohesion[34] noted that older people are often regarded as a homogenous group and negatively stereotyped as passive recipients of care and support. However, older people have diverse interests and many continue to live active lives and make major contributions to society long into old age. Professor Bloom has argued strongly that Portugal and other countries should not be *"victimized by our pre-conceptions of age-*

ing and fail to act.”[35] There are, as he describes, many benefits to come from the remarkable success of keeping so many people alive for so long – not least, taking advantage of the *“immense social capital they (older people) have to offer, including wisdom, experience, moral authority, and leadership.”*

OBESITY AND INACTIVITY

Obesity, poor diet and lack of physical activity are a worldwide health concern and affect all ages in Portugal. Physical inactivity is now identified as the fourth leading risk factor for global mortality.[36] Portugal has a significant obesity problem, particularly with children and adolescents, which is rapidly worsening. Estimates suggest that complications associated with obesity are responsible for up to 10% of health costs.[37] The figures are stark:

- **Children** – According to the WHO reference system, the prevalence of overweight and obesity were 37.9% and 15.3% respectively among 6-8 years old in the first data collection from the Childhood Obesity Surveillance Initiative Portugal.[38]
- **Adolescents** – Portugal has the highest level of reported overweight (including obesity) among 15 year olds among the EU24 countries.[39] Recent research on obesity in Portuguese adolescents indicates that there is an even higher prevalence of excessive weight than found in national data, with 36.6% of girls and 38.8% boys classified as overweight or obese.[40]
- **Adults** – In 1996, 10.3% of Portuguese adult males and 11.4% of adult females had a BMI of over 30 kg/m2[41]; by 2006, this had increased to 16% for males and 16.9% for females representing an additional 55.3% and 43.9% for males and females respectively over a period of ten years.

There is now general consensus that the causes of rising levels of obesity are complex and linked to environmental, commercial, social, behavioural and genetic factors.[39] In the Portuguese population specifically, increasing obesity is associated with trends in excessive energy intake, at 3747 calories on average per person in 2003 and low rates of leisure-time physical activity.[11] Another study found low levels of physical activity, as well as parents’ educational level, to be important determinants of childhood and adolescent obesity in Portugal.[11] The biggest factor, however, remains the levels of type of food consumed with particular reference to sugar and sugary drinks for children. No amount of exercise can counteract these very high calorie intakes.

Portugal has a significant obesity problem, particularly with children and adolescents, which is rapidly worsening.

Undertaking physical activity in childhood and adolescence has multiple benefits for health over the life course. Across the Portuguese population only 36% of participants aged 10-11 achieved the recommended 60 minutes of physical activity per day, while in adulthood, around 70% of participants reached the recommended 30 minutes.[42] Women and girls exercised significantly less than men and boys in all age groups, suggesting there is a real need to target policy towards encouraging exercise towards women and young people.

In 2004 the National Programme against Obesity[43] was launched with wide ranging aims, including to identify and promote cross-cutting actions with other sectors of society, including agriculture, sport, environment, education, local government and social security to improve diet; to develop electronic tools to aide healthy meal planning; and to foster local networks to monitor best practices in promoting healthy eating. To date, there is no evaluation of activity, and there appear to have been difficulties in implementation, particularly with regard to cross-sectoral collaboration and security of funding.

MENTAL HEALTH AND WELL-BEING

In a survey of mental well-being, 71% of Portuguese people reported having more positive experiences in an average day than negative ones, which is lower than the OECD average of 80%.[6] Portugal has the highest level of antidepressant use in the EU at 15% prevalence, which is double the EU average.[44] Portuguese people are also relatively more likely to seek professional help for a psychological or emotional problem than other European populations. Death rates from suicides have increased since 1995, though still remain below the EU average.[39]

There are also increasing concerns over the impacts on mental health of unemployment and stress. While these affect people of every gender, men tend to show a greater tendency towards depression and are generally more reluctant to seek help from professionals or friends and family. There is strong evidence across Europe that young men are a high-risk group for suicide, and rates have increased across the region since the onset of the economic crisis.[45]

HEALTH INEQUALITIES IN MINORITY GROUPS

Portugal has high levels of social and income inequality, with significant disparities in health and well-being between wealthier and poorer sections of the population. UN and OECD data reports have shown Portugal to have the highest

GINI coefficient score in Europe, suggesting that it is one of the most unequal societies.[46] The richest 20% of the population are estimated to earn more than six times the amount of the poorest 20%.

While there is a shortage of reliable demographic data, the existing evidence suggests that the most vulnerable groups include the elderly and children in poverty, the rural poor, ethnic minorities, immigrant groups, and the long-term unemployed.[47] These groups are significantly more likely than the rest of the population to suffer from poor health and experience extended periods of poverty, unemployment and social exclusion. Processes of exclusion should be addressed rather than simply focussing on the characteristics of excluded groups, and is a key area for further research.

There is also some evidence that people with disabilities in Portugal experience overlapping processes of exclusion, particularly with regard to physical access and in how they are perceived by the wider public and state institutions as victims rather than full citizens.[48]

On the other hand, Portugal is very progressive with regard to lesbian, gay, bisexual, transgender and intersex (LGBTI) rights. In 2007, the Penal code was amended to equalize the age of sexual consent, and to criminalize domestic violence in same-sex relationships, bringing this in to line with treatment for heterosexual couples, and gay marriage was legalised in 2010.[49]

GENDER

As well as biological sex differences, fundamental social differences exist in the way women and men are treated, and these gender relations affect health to varying degrees.[21] Portugal has shown some positive progress in addressing gender inequalities. In educational attainment, girls outperform boys: with a 2009 survey showing that 61.3% of women aged 20-24 had completed upper secondary school in comparison to 50% of men,[50] and more women graduating from university than men. In the political system, while there are still many more men in parliament than women, there is greater representation of women than the EU average, with women holding 66 out of 230 seats (28.7%) from the 2011 elections. Yet, only 7 women held executive positions in the 20 biggest companies listed on the Portuguese Stock Index (PSI-20) in 2008, compared to 116 men (94%).[51]

The gender balance in the wider labour market is rapidly shifting, with more women in employment than men for the first time. Despite this, gender discrimination in wages is widely reported,[52] with Portugal having a particularly high gender wage gap compared to other European countries.[53]

While life expectancy levels in Portugal (82.6 for women, 76.5 for men) are close to OECD averages, Portugal has comparatively low levels of healthy life years (56 for women, 59 for men), and has the greatest gender gap favouring men, meaning that Portuguese women spend a significantly greater number of years living in poor health.[39] A study on gender disparities in health, showed that women in Portugal were more likely to report worse self-rated health, higher prevalence of hypertension, chronic pain, cancer, and depression.[54]

Time is a particular barrier to accessing women's health services, particularly for those who work long hours, both in employment and in the home. For many this leaves little time to self-care, to go for check-ups or screenings, or to improve their knowledge of health issues. Women's health clinics are often run in the mornings when they are likely to be at work. Numerous appointments with a primary care practitioner are needed for even routine screening tests such as cervical smears. Many women are therefore unable to access screening tests that could improve detection and early intervention rates.

The key concerns with regard to men's health are relatively high levels of alcohol consumption and related morbidity and mortality compared to other OECD countries.[39] Mortality from road accidents is the leading cause of death among children and young people, especially young men, in many countries across Europe, including Portugal.

REGIONAL DIFFERENCES

Overlying all these other issues, there are significant differences in wealth and health indicators between Portugal's metropolitan areas around Lisboa and Porto, and the interior regions. Many living in rural areas continue to live in relative poverty and may have to travel large distances to access quality health services,[55] suffering disproportionately the consequences of poor geographical access. Poverty is particularly prevalent in the South (Alentejo), where very high percentages of families living in extreme poverty are recorded.[47] However there is little data on health outcomes in these areas, making it difficult to target policies appropriately.

POLICY APPROACHES

A great deal of international and national health policy is now shaped around understanding of the determinants of heath and the need to prioritise health promotion and disease prevention. Portugal's National Health Plan 2012-2016[56] is based on this, as is the European Region of the WHO's 2020 plan;[57] whilst many global WHO policies advocate these approaches. The Portuguese and European strategies contain references to taking a "life course" approach to health and to "Health in all policies".

The WHO European review of social determinants[21] has described the life course model as the best way to plan action on the social determinants of health in order to protect current and future generations from poor health, to promote well-being, and reduce health inequalities. Put very simply, it is an approach which seeks to address the needs of people at different stages of life and create an inclusive package of measures: from good reproductive and early childhood services via improving working environments to providing opportunities for exercise and social activity later in life. It is an inclusive model which encourages collaboration across a broad spectrum of stakeholders, across clinical specialities and the social and health sciences, and which involves citizens, academics and policy makers.

Health in All Policies refers to the inclusion or internalisation of health in other policies that shape or influence the social determinants of health, such as education, housing, transport, environment and so on.[58] The aim is to integrate consideration of health, well-being and equity during the development, implementation and evaluation of policies, and in practice 'requires a new form of governance where there is joined up leadership within governments, across all sectors and between levels of government".[59]

> *"in many cases, the best choices for health are also the best choices for the planet; and the most ethical and environmental choices are also good for health."*

In the European context, this practice has developed into a "co-benefits" approach, through which multiple sectors *mutually benefit* from policies, encouraging greater cross-sector collaboration and leading to society-wide improvements.[60] Such a whole-of-society approach should also reach beyond government departments in its efforts for collaboration, supporting action and cohesion at the local level, encouraging the development of partnerships with civil society and a range of civic partners.[21]

Ilona Kickbusch has written about the growing linkages between health promotion and sustainability, as "*in many cases, the best choices for health are also the best choices for the planet; and the most ethical and environmental choices are also good for health*".[61] Too frequently, sustainability and health are dealt with in separate debates and policy arenas. More effort is needed to link these to ensure that they support each others' normative and strategic goals.

The Adelaide Statement on Health in All Policies from 2010[59] provides a clear overall perspective on the approach:

> *"Since good health is a fundamental enabler and poor health is a barrier to meeting policy challenges, the health sector needs to engage systematically across government and with other sectors to address the health and well-being dimensions of their activities. The health sector can support other arms of government by actively assisting their policy development and goal attainment.*
> *To harness health and well-being, governments need institutionalized processes which value cross-sector problem solving and address power imbalances. This includes providing the leadership, mandate, incentives, budgetary commitment and sustainable mechanisms that support government agencies to work collaboratively on integrated solutions."*

The concept has already been introduced by the Portuguese Directorate-General of Health in its report of 2007.[33] However, Portuguese authors have noted the difficulties Portugal faces in this area, particularly that political-administrative culture and traditions are not favourable to fostering inter-sectoral collaboration, and that health system management structures are highly fragmented.[62]

IMPLEMENTATION

Portuguese policy on the determinants of health has developed in recent years but implementation has lagged behind. There are now beginning to be examples of cross-cutting action at scale in many countries and guidance on making them effective.[63] In addition, legislation and fiscal policies can play a significant role by for example, reducing the use of tobacco and putting heavier taxes on unhealthy products. These could be taken further both to prevent ill-health and to raise revenue – as suggested in Chapter 7.

However, there are some very practical problems which make cross-cutting actions difficult to implement. There are difficulties in aligning priorities, budgets and accountability and there can often be problems of "territorialism" and ego that need to be subsumed in a shared programme. Working Group 2 pointed to these problems in describing the difficulty of: "*building participative policy-making … despite the several official written documents about the importance for integrating social determinants of health and equity into public policies, the practice is not yet in place.*"

It did, however, suggest that there were some hopeful beginnings in "*inter-ministerial commissions for relevant health issues as education, environment, tobacco, radiation … pilot health impact assessments …*" and wrote that "*Some important networks are advanced in this process*".[64]

The Commission believes that there is a much bigger role here for municipalities than they have traditionally played. Local communities are the natural place for bringing together all the different policy areas from education to transport and economic development to health. Different sizes of municipalities have different capabilities and capacities but all could play a role. Some already do, as is shown in the following examples.

In parts of Western Europe, public health has long been a local role. In some countries, such as Sweden, health services are almost entirely the responsibility of local authorities. England has now adopted a new policy whereby *Health and Well-being Boards* are created as formal committees in each of the top-tier local authorities. The local authority is receiving new powers as well as new budgets and is required to work in partnership with the NHS locally and other partners. Even without additional powers and funding, some municipalities in Portugal are very active in driving improvement locally within their existing mandate.

Local communities are the natural place for bringing together all the different policy areas from education to transport and economic development to health.

GOVERNANCE FOR HEALTH

One of the ways to accelerate cross-sectoral working is to bring representatives together into governance structures. The Commission, building on a recommendation from Working Group 1, on Health Services and Public Health, recommended in the first chapter of this report that the National Health Council should be established as a whole of society alliance which could own and refine the vision for the future, take an overview of the system and advise on policy in line with this vision. It would be representative of citizens and all sectors of society and independent of politics and report to Parliament, the Minister of Health and the public.

This sort of governance structure or alliance is also needed at municipality level. Exactly how this would be done would vary from area to area depending on circumstances. However, the Commission noted that municipalities already have regular meetings of the "social sector", which includes education, social services, housing and others, in order to plan and execute programmes jointly. The SNS and health organisations are not normally involved; yet there would be obvious benefit from doing so. There are excellent examples of municipalities taking action on health with great benefit to their populations as the following two examples show.

Municipality of Oeiras – “Mexa-se Mais”

The municipality of Oeiras, near Lisbon, promotes informal as well as formal sports, with huge events that mobilise 100,000s of people in leisure activities, walking, running, pedestrianized, invest in communicating – their slogan is ‘move yourself more!’.

The mission of the project is to make the population of Oeiras more active by increasing all forms of physical activity and sport. The municipalities aim to do this by informing citizens about the importance of following active, promoting exercise and regular physical activity with consequent improvement of well-being and quality of life.

They also seek to empower citizens in the decisions around the programme, motivating them to use available spaces effectively. This is a pioneering program and a national and international example of best practice which supports scientific research in the area of health promotion and exercise.

One example is ‘activity in the open air’, which is aimed at the whole family, encouraging group physical activity in places of historical and cultural interest of the municipality of Oeiras. Another is the programme aimed at the older population with the goal of promoting active aging through regular physical exercise, including strength training, fitness classes and swimming.

Portuguese Network of Healthy Cities – Health Promotion Office, Miranda do Corvo

The Portuguese Network of Healthy Cities is an association of municipalities whose mission is to support the dissemination, implementation and development of the Healthy Cities. Founded in 1997, the Network aims to support and promote the development of local strategies to promote healthy lifestyles, and encourages cooperation and communication among municipalities.

The municipality of Miranda do Corvo set up a ‘Gabinete de Promoção da Saúde’ (Health Promotion Office) to promote the all round physical, mental and social well-being of young people. Their goal is to develop a close relationship between the education community and the Health Centre to promote healthy behaviours. Priority areas include mental health, oral health, safety and preventing accidents, sexual and reproductive health, and the target users are school age children. The project enabled young people to come together to access guidance, advice on nutrition and physical activity.

Whilst these proposals only deal with the national level and municipalities, the principles of cross-sectoral engagement and alliances apply to all health and care bodies. The Commission suggests that all these bodies examine how they can best work with partners in other sectors and consider whether any new partnership or governance structures and processes are needed.

CIVIL SOCIETY AND VOLUNTARY ORGANISATIONS

The importance of there being strong civil society and informal networks of care has been emphasised in both this and the last chapter. They have the potential for having major impacts in terms of health, social cohesion and the sustainability of the whole health and care system.

The current arrangements for health organisations engaging with and supporting these organisations are highly variable across the country, with some like the Portuguese Diabetes Association (APDP) being highly visible and well integrated with the SNS and others operating almost entirely separately from the formal health and care services. The Commission believes that, in order to maximise benefits, the Ministry should work with municipalities and health organisations to find better ways to promote, support and engage these organisations at all levels of the health and care system.

PUBLIC HEALTH

This approach requires a very much strengthened public health service in Portugal to provide the expertise and understanding needed to have the greatest impact on health.

Working Group 1 argued for strengthening public health within the framework of the WHO health strategy for the European Region, Health 2020.[65] This adopted the definition of public health proposed by Acheson:

> *"Public health is the science and art of preventing disease, prolonging life and promoting health through the organized efforts of society".*[66]

The framework identified the *Essential Public Health Operations* in the domain of service delivery as being:

- Health protection, including environmental, occupational, food safety and others
- Health promotion, including action to address social determinants and health inequity
- Disease prevention, including early detection of illness

In addition there needs to be a group of intelligence and enabler operations to support this covering: surveillance; monitoring preparedness for response; informing health assessments; governance; PH workforce; funding; communication; and research.

The Commission heard a great deal of comment on the current weakness of the Portuguese public health system. Despite some very good institutions and individuals it was felt to be patchy, generally weak and under resourced. Accordingly, Working Group 1 recommended that there needed to be a thorough review of current capabilities prior to decisions about strengthening the service. This sort of process has been undertaken in other countries in Europe for similar reasons. The example below shows how Norway has strengthened its public system with new legislation and new capabilities and capacity. Given the importance of public health to other parts of government as well as health, the Commission believes that there should be a government wide process to strengthen public health. This will undoubtedly need some additional resource but will also require some changes in organisation and re-direction of some current staffing and resources.

> *"Public health is the science and art of preventing disease, prolonging life and promoting health through the organized efforts of society".*

INTERNATIONAL EXAMPLE

Norwegian Institute for Public Health

The Norwegian Institute of Public Health (NIPH) is a driving force in improving the health, quality of life and legal protection of the population. National and international research and health surveillance collaboration gives valuable insight into factors that affect public health and how it can be improved. The NIPH also collaborates with the WHO, EU, EEA, sister institutions, universities, organisations and health authorities in low- and middle-income countries on global health issues. The NIPH is placed directly under the Ministry of Health and Care Services, alongside the Norwegian Directorate of Health, the Norwegian Board of Health Supervision and the Norwegian Medicines Agency.

The vision of the institute is very simple – a healthier population. The aim is to prevent disease. The main goals are to:

- be prepared for acute health threats
- advise and provide services that improve public health
- have an overview of the health of the population and factors influencing public health
- gain knowledge of what causes common diseases and what gives people better health

The NIPH bases its advice and services on research and health surveillance. The work is based on these core values; *professionally sound, reliable, innovative, open* and *respectful.*

DATA AND INFORMATION FOR PLANNING AND POLICY ANALYSIS

Working Group 1 also made the point that:

> *"We need more reliable information and data about Portuguese society and the population, and multidisciplinary analysis of the complex causes of poor health discussed in this paper. The lack of demographic data makes it difficult to adapt standard policy models to work for the Portuguese environment. There are numerous databases operated by policy-makers, administrators and health professionals, but these are not integrated and interoperable.*[62] *There is also a need for health professionals and other experts working in health to work more closely with their colleagues in the disciplines of social sciences, economics, and public policy to improve health across society, and fully make use of Portuguese expertise."*

This is a recurrent theme throughout this report. It was also reported as a significant issue in the 2010 WHO assessment of the health system. The assessment report stated:

> *"Throughout the course of this performance assessment, a number of health information gaps were identified that could restrict the capacity to develop, analyse and monitor the effectiveness of policy options, as well as making it difficult to formulate an assessment of performance in some important areas. Good health system information is also required to support transparency and accountability within the system. For example, there were limited data on measures of safety and quality of health care. It is also difficult to assess and monitor the extent of socio-economic inequalities in health or in access to health care services".*

This major problem needs to be addressed through improved systems as well as through greater openness and transparency.

CONCLUSIONS AND RECOMMENDATIONS

The arguments for cross-sectoral action to improve health and achieve other social goals are compelling. They will contribute to the re-shaping of the welfare state in Portugal and help create greater social cohesion and inclusion.

This is part of a global movement. Worldwide, there is already development of healthy cities and workplaces, healthy schools, healthy eating and, in some sectors of the population, fitness and exercise. This now needs to be done at a far larger scale to make significant impact on the health of the population.

This chapter has drawn heavily on Working Group 1's deliberations and on input from many different stakeholders. Following discussion with the Group and further deliberation, the Commission has decided to make 3 recommendations here. The Commission's recommendations in this chapter are designed to create the leadership, knowledge and expertise that are needed for this.

Figure 1 • **Recommendations**

RECOMMENDATIONS

9. **MUNICIPALITIES.** Municipalities, which already play leading roles in the well-being of their populations, should include health and health organisations in their local social welfare partnerships to support cross sectoral planning and working.
10. **CIVIL SOCIETY.** Municipalities, health and commercial organisations and the appropriate ministries should work together to find better ways to promote, support and engage voluntary organisation and informal networks of care at all levels of the health and care system.
11. **PUBLIC HEALTH.** The Government, relevant Ministries, the SNS and public health institutions and associations should work together to strengthen public health functions across the whole health system at all levels, with knowledge of and expertise in public health becoming a larger part of every health worker's education and training. Consideration should be given as to whether new legislation on Public Health is needed to support these recommendations.

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The continuous pursuit of improved quality and the application of knowledge and technology

4

Early treatment, high quality and evidence-based services are good for patients – and also reduce waste and save expenditure. There needs to be a focus on continuous quality improvement and systematically applying the evidence of what works, everywhere and at all times. Portugal must position itself to take full advantage of future advances in science and technology.

PORTUGAL MUST POSITION ITSELF TO TAKE FULL ADVANTAGE OF FUTURE ADVANCES IN SCIENCE AND TECHNOLOGY

Quality of care, patient safety and the need to ensure that treatment is based on the latest knowledge are key issues for patients and health professionals alike. Advances in bio-medical and information science and technology are providing new opportunities for the improvement of care and services every year. At the same time, better understanding of the methods for improving quality is bringing enormous benefits in care and in identifying the most effective and appropriate treatments and technologies.

The Commission has not attempted to predict what advances might be made in the next 25 years but has, rather, concentrated in this chapter on how Portugal can best position itself to take maximum advantage of the gains that science and technology will bring. It proposes four strategic actions to do this:

- Firstly, to ensure that the approach of continuous quality improvement is adopted throughout the system as a means both of promoting quality and of ensuring that new scientific and technological advances can be systematically integrated and implemented everywhere.
- Secondly, to create a new national service of SNS Evidence which will ensure that new technologies and therapies are properly evaluated and that evidence is available everywhere within the system at all times to both citizens and professionals.
- Thirdly, to implement fully the Electronic Health Record as the essential underpinning of an integrated and high quality service and to link it with applications that support both the flow of information and access to evidence.
- Fourthly, to develop effective collaborations between the SNS, the research community and industry.

These four strands are dealt with in turn in this chapter.

QUALITY

There have been enormous developments in the methodologies of continuous quality improvement in recent years and in its application to health and health care. These developments improve quality but, the Commission believes, can also play a crucial part in the successful implementation of policies and use of evidence within the system. The simple point here is that it is one thing to have a good policy or good evidence but quite another thing to implement it in practice. Implementation requires clarity of purpose, accountability, evaluation, an understanding of how systems work and a shared methodology. The approach to quality and quality improvement described here provides for all these elements.

Looking at quality in the round, Portugal has a sound foundation to build on. It has good professional education and practices and much has been done in recent years to measure and improve quality and safety and develop appropriate guidelines. However, there is little consistency in data, measurement is undertaken differently in different areas, new technologies and therapies are not systematically assessed, and practices vary widely among clinicians, organisations, and regions without adequate understanding or explanation.

> Looking at quality in the round, Portugal has a sound foundation to build on. It has good professional education and practices and much has been done in recent years to measure and improve quality and safety and develop appropriate guidelines.

Quality theorists such as Joseph Juran distinguish between "quality control" (the degree to which a particular product or service meets a certain standard), "quality improvement" (processes and management methods through which the performance of a product or service gets better over time), and "quality planning" (methods by which novel products and services are discovered or invented, and introduced safely and effectively). All three matter to those served ("customers") and a complete system for quality management attends to all three.

What unifies quality control, improvement, and planning, is a single view of the nature of "quality," itself. Simply stated, "quality" is, in the modern view, "the degree to which a product or service meets and exceeds the needs and requirements of the people served – customers". In the commercial world, organizations thrive if they provide value to customers, and they wither if they do not. Health care worldwide has begun to adopt this view of quality in the past quarter-century, and it has begun slowly to replace the prior, professionally dominated views according to which, in the words of sociologist Eliot Friedson, "*Professions are work groups that reserve to themselves the right to define the quality of their own* *work*."[1] This transition (from professionally-centered to customer-centered views of quality) is a challenging one and far from complete yet, but more and more widely accepted as offering greater benefits to patients and society as a whole. It is a key underlying theme of this report.

Health care globally has a mixed record on quality. On the one hand, there has been astonishing progress in health outcomes with remarkable improvements in the length and quality of life. On the other hand, there are disturbing defects in patient safety, patient-centred care, and reliability of care and outcomes. As Working Group 1 said:

> *"It has come as quite a shock to modern societies that often health care systems do not deliver care with as much quality as desired."*[2]

Patient safety statistics first became a matter of public concern globally during the early 1990s when it was found that the burden of disease and deaths from medical errors (so-called "adverse events") was surprisingly high. Despite far greater attention to patient safety, estimates suggest that still one in ten patients (indeed, by some estimates, one in three) globally is harmed while receiving health care in well-funded and technologically advanced hospital settings. This burden may be significantly higher in resource poor settings.[3]

In 2004, the WHO launched a patient safety programme, underlining the importance of patient safety as a global healthcare issue.[3] The safety of patients or "*freedom from accidental injury*" in healthcare settings[4] is now very often the first goal of health care quality improvement programmes, as it has been in Portugal. Globally, campaigns have focused on the use of simple but highly effective messaging and tools to improve hand hygiene and the use of checklists to ensure safe surgery. Much of this has been based on lessons drawn from safety methodologies and practices first developed outside health care, especially in other high-risk industries.

Patients recognise this picture. On the one hand, surveys show how grateful they are, with over half (57%) of respondents who had recently visited a hospital saying they are satisfied with the level of care in 2011.[5] On the other, complaints are rising.[6]

Making improvements requires system-wide action. It involves both clarity about the aims that are being sought and mastery of the methods that can achieve them. Working Group 1 sets the scene in writing:

> *"Priority conditions should be identified and strategies, goals and action plans developed so as to attain substantial improvements in each. To apply these priorities, a set of actions is recommended: practice should be evidence-based and care coordinated around patients' needs; quality and performance should be*

measured and evaluated and information fed back to the providers in simple ways; information technology and payment mechanisms should support and not hinder these efforts.

At least some of the structures and processes in which health care professionals and organisations function will need to be changed. Four main areas are identified: applying evidence to health care delivery; using information technology; aligning payment policies with quality improvement, and preparing the workforce." [2]

This report addresses all these issues here and in the following chapters.

Modern quality improvement methods have to date largely been applied to health and care services rather than to areas such as health promotion and protection. However, the principles of improvement described here were derived from other industries and can apply to any activity. These principles need to be understood and used widely across the health and related sectors. They should be an integral part of the whole strengthening of public health described in Chapter 3.

THE COSTS OF POOR QUALITY

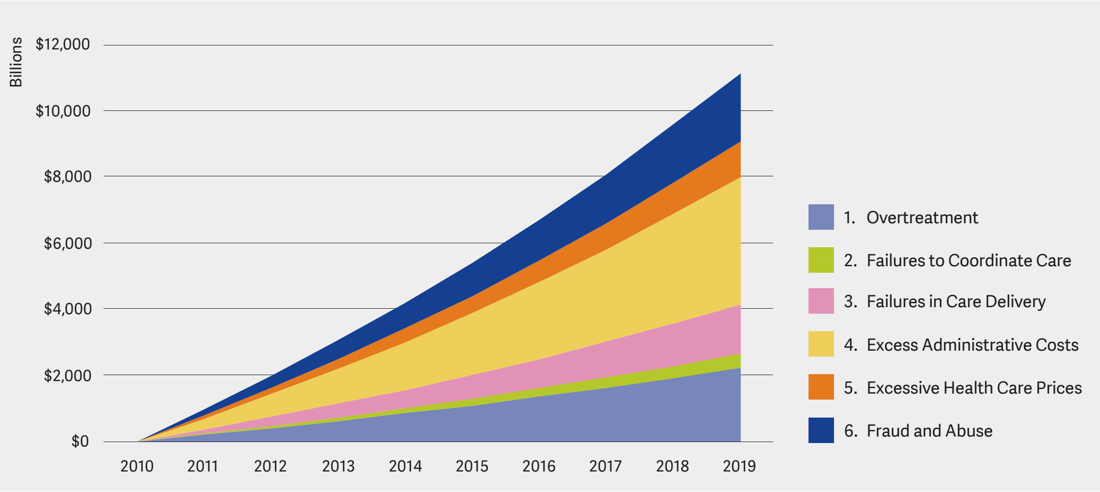
Poor quality health care is not only bad for patients, it is also very expensive. For example, tests or treatments not done well the first time, need to be repeated. Keeping people waiting for attention is costly and may lead to increased suffering and avoidable downstream care with acute problems turning into chronic ones. Poor coordination between health workers is wasteful. Patients who get bed sores or infections from a stay in hospital suffer from poor quality care and use more SNS resources than those who are looked after well. These examples demonstrate that improving quality does not automatically increase costs. In many cases, better quality reduces costs. Professor Noriaki Kano has provided a useful taxonomy in identifying three types of improvement:

1. Reducing defects. Examples of health care defects include healthcare acquired infections, medication complications, surgical mishaps, and long waiting times.
2. Reducing the cost of production, while maintaining or improving the outcomes and patient experience. Examples in health care include avoiding duplicative testing, reducing unnecessary treatments, and eliminating administrative complexity and paperwork. They also include redesigning services with the more use of technology, different staffing models and greater use of ambulatory and community care.

3. Adding a new feature or a new product or service. Examples in health care include new therapies, diagnostic tests or services.

The first two types of quality generally reduce costs – often by eliminating waste – whilst the third type generally increases costs. In most industries efforts are made to ensure that the costs of the third type are met through savings from the first two. There appears to be enormous scope for this in health care. A US study suggested that 30-40% of US expenditure on health care is wasted as shown in Figure 1. This amounts cumulatively to around $11 trillion between 2010 and 2019.

Figure 1 · **Waste in the US health system**[7]



US Health Care System Theoretical Waste (Aggregate Waste 2011-2019)

This study identified six categories of waste. There has not yet been a similar study on Portuguese health care, but experience would suggest that there is plenty of waste to be eliminated within, at least, the first three categories of over treatment, failures to coordinate care and failures in care delivery.

In many ways, the unification of cost reduction with quality improvement has reached its apotheosis in the so-called “Toyota Production Process,” or “lean production.” Pioneered by Toyota in the last half of the 20th century, lean production orients management, workforce knowledge and effort, planning, and design all toward the continual removal of waste from all phases of production. “Waste” in this view encompasses a wide array of activities and investments that do not add value to the experience of customers. Examples include inventory, unused space, scrap, delays, lost ideas from the workforce, overproduction (making things that people do not want or need), duplication, administrative barriers, and so on. In many industries today, organizational survival depends on aggressive and continual reduction of non-value-added activities in production.

A growing number of forward-thinking health care organizations in the past decade have discovered, adapted, and used lean production methods to reduce their costs while improving care, with sometimes stunning results. Examples include Denver Health, Virginia Mason Medical Center, and Theda Care in the United States. Their stories have been written up as case studies.[8] The widespread adoption of *lean production* methodologies and leadership methods could yield major gains in resource savings in Portugal as elsewhere.

> The widespread adoption of *lean production* methodologies and leadership methods could yield major gains in resource savings in Portugal as elsewhere.

QUALITY IMPROVEMENT

Quality improvement in health has been developed into a science and a set of systematic procedures largely through the work of the Institute for Healthcare Improvement, which has adapted and developed learning from other industries and applied it to health care. Four core principles are noted here:

1. **"Quality" is always multidimensional – it is not a single measure.** Clarity about those dimensions can help guide effective control, improvement, and planning. Working Group 1 has proposed that Portugal adopt the six dimensions of quality articulated by the Institute of Medicine in 2001:

   a. Safety – Avoiding harm to patients from care
   b. Effectiveness – Aligning care with the best of clinical science
   c. Patient-centeredness – Customising care to the needs, resources, values, and background of each individual patient and carer
   d. Timeliness – Avoiding unnecessary delays for patients and clinicians
   e. Efficiency – Reducing waste in all of its forms
   f. Equity – Closing racial, ethnic, and other gaps in health status and care

2. **Set Bold Aims for Improvement**. Improvement accelerates when leaders identify clear, measurable, and bold aims. In health care, such aims could be to reduce re-admissions to hospital, reduce medication errors, or reduce

the number of bedsores or hospital acquired infections. The starting position and the methods of measurement need to be clear, transparent, trustworthy, and objective.

3. **Understand production as a system.** Quality is always the result of a range of different, interacting causal factors. The pursuit of excellence requires attention to those system dynamics, and, of course, changes in the system. Airlines have achieved impressive safety records by checking and double-checking problem areas – "*doors to manual and cross check*" – such safety-first procedures don't generally happen in health care. Problems occur because the system was not designed to stop them. In the words, often used by IHI: "*Every system is perfectly designed to achieve exactly the results it gets*." Those who desire new results, must seek a new system.

4. **All improvement is change – although not all change is improvement**. Success in making sustainable improvements requires appropriate changes at nested levels within a health system: from the patient consultation to organisational processes and national policy. An improvement that a clinical team wants to make in the way a particular patient is cared for by, for example, treating the patient at home rather than in a hospital may not be effective unless organisational systems and financial arrangements are also changed to allow this to happen. Similarly, there may be no point in introducing a new national policy unless there are related changes in what clinicians and organisations do locally.

   Don Berwick has described the need for alignment of efforts across the whole system as a "Chain of Effect" operating at four levels – in the experience of the patient, within the service itself, within the healthcare organisation, and within the wider health care environment including all the elements of financing, regulation, accreditation, education and social policy. [9]

IMPROVEMENT METHODOLOGIES

Modern quality control, improvement, and planning all rest on extensive scientific foundations in statistics, operations engineering, personal and organizational psychology, and more. From these sciences, emerge effective techniques that can be harnessed by organizations, including health care organizations, to achieve performance breakthroughs, and to scale-up and spread improvements within and among organizations. What unifies all of these modern approaches is a clear shift from reliance on inspection and compliance for improvement to reliance on widespread learning, growth or knowledge, and workforce participation.

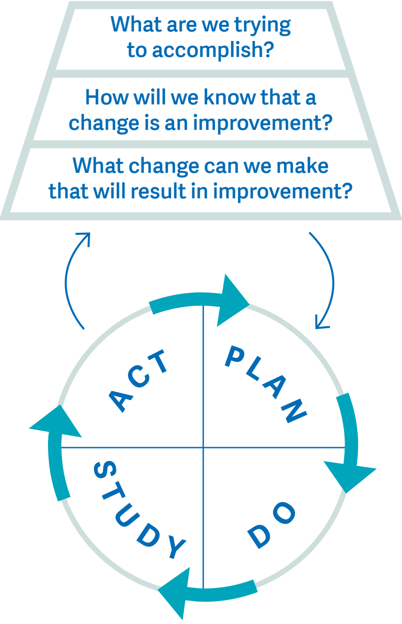
A few examples of the modern methods are these:

- **The "Model for Improvement"**, seen in Figure 2, guides people through four steps (three questions and a test) as they try to make a process better:
    - › Set an aim for improvement ("What do we want to accomplish?")
    - › Establish measurements (which can be quantitative or narrative) ("How will we know if a change is an improvement?")
    - › Identify a system change worth testing ("What change can we make that might produce an improvement from the viewpoint of the customer?").
    - › Test the change on a small, informative scale. (Using the Plan-Do-Study-Act Cycle (PDSA) for learning from the test).

  These four steps for testing and learning are now in one form or another nearly universal in modern approaches to improvement in any industry. Given a problem such as the need to improve care for people arriving after a heart attack in an Accident and Emergency Department, the staff directly involved are asked to *plan* changes that might help, to implement them quickly (*do*), to *study* what happens, and to *act* accordingly based on what they have learned. The clinical evidence about what is needed may be very clear; this approach enables people to implement it effectively within their work environment. This learning cycle can be repeated over and over again, so that confidence and skill increase over time as each change is refined and adapted.

  This cycle can be used regularly at every level in an organisation so that it can become a constantly "Learning Healthcare System" capable of continual improvement.[10, 11]

Figure 2 · **The model for improvement**[12]



- **The "Breakthrough Series Collaborative" approach to shared learning**: pioneered by the Institute for Healthcare Improvement in the mid-1990s, establishes cooperative projects among organizations that are trying to improve the same or similar processes, products, or services. By working together and staying in touch, they can learn faster and share lessons (The rubric for Breakthrough Series Collaboratives is "All Teach – All Learn").[13] Collaboratives are now used throughout the world for accelerated improvement. The example below shows how this was used in England to improve care for heart attack victims.

- **The "Improvement Campaign" approach**: also pioneered by IHI in the early 2000s, attempts to bring collaborative improvement to a massive scale by supporting a leveraged architecture of communication, social support, field support, and measurement linking literally thousands of organizations or individuals in a shared and intensive endeavour. The example below describes IHI's first such effort which was the "100,000 Lives Campaign." This sought in 18 months to involve over 3,000 US hospitals in adopting six evidence-based patient safety practices with the aim of reducing deaths in those hospitals by 100,000 in the period. Campaigns for improvement have been adopted and adapted in numerous nations since, including Sweden, Japan, Denmark, Scotland, New Zealand, Wales, and more. See the third example below.

INTERNATIONAL EXAMPLE

Using the breakthrough collaborative model to improve care for heart attack victims in England

The English NHS used a Breakthrough Collaborative to improve survival rates from heart attacks. In addressing the problem, different hospitals chose to do things as simple as making sure cardiac drugs are stored near the ambulance receiving bay, allocating specific trolleys for suspected heart attack patients and improving the paging systems for cardiologists. Over time, through action at higher levels, nurse practitioners were given extra training and ambulance staff were trained in pre-hospital care and given authority to inject *clot-busting* drugs following clear protocols.

These approaches can help surface best practices. In this English example, the NHS was eventually able to describe the most effective ways of improving care for heart attack victims in A and E Departments and to help all hospitals achieve them, thereby contributing significantly to reduced mortality.

INTERNATIONAL EXAMPLE

The 100,000 lives campaign in the US

The IHI's *100,000 lives* campaign[14] was a nationwide initiative in the United States, launched in 2004, which identified 6 evidence based interventions which if applied accurately and universally all the time would save 100,000 lives in 18 months in US hospitals.
These were:

- Deploy rapid response teams to treat patients before cardiac arrest and facilitate fast transfer to intensive care units.
- Deliver reliable evidence based care for acute myocardial infarction.
- Prevent adverse drug events through medication reconciliation.
- Prevent central line infections through a simple care bundle.
- Prevent surgical site infection through guidelines on pre and post-operative care and appropriate use of antibiotics.
- Prevent ventilator-associated pneumonia through use of guidelines.

The campaign was very successful and the approach has been used elsewhere at national scale. [15,16]

THE PORTUGUESE EXPERIENCE

A significant number of Portuguese organisations and people are well versed in these methodologies and are applying them within their areas. There is now a Portuguese quality network for research which brings together many researchers and institutions around the country. Moreover, there have been several national initiatives on quality. As Working Group 1 states:

> *"Portugal has had a national strategy for ensuring and improving health care quality for some years. This includes an accreditation component, and recent activities have also included both the production and implementation of a large number of evidence-based clinical guidelines and a system for reporting adverse events. However, the translation of these national goals to the field has been difficult."* [2]

The difficulties, alluded to above, are that there are three different and incompatible systems of accreditation in existence and there are different methods of collecting information about adverse events. It is therefore difficult to obtain an understanding of quality in Portugal. Moreover, whilst clinical guidelines have been produced, there appear to be no arrangements for assessing whether they are being implemented, let alone any incentives for ensuring their implementation or sanctions for failure to do so.

Working Group 1 reports that:

> *"More recently, and in part in an attempt to solve these difficulties, it has been determined by the Ministry of Health that all health providers must have a structure responsible for quality assurance and improvement and that all health services also have to have a consistent strategy for quality assurance and improvement, in line with an up-to-date national strategy."*

However, the Commission noted that there are currently three bodies with some responsibilities for quality. This appears to be both wasteful and counterproductive:

- The Directorate General of Health which has set out a ten year strategy for quality improvement in Portugal and which is about to be revised
- The Health Regulatory Authority which has launched a benchmarking scheme for analysing safety and quality in hospitals in 2012 and is publishing the first results of the programme
- The Finance Department which has responsibility for publishing indicators of performance in hospitals and has now included a number of quality indicators in its programme including numbers of re-admissions and infection rates

These various initiatives have not yet produced substantive results, nor generated significant momentum or become a major priority within the health service. The members of Working group 1 and other Portuguese leaders in this field have argued that a more systematic and integrated approach to promote safety and quality improvement is needed.[17]

KNOWLEDGE

Knowledge is, and always was, a vital resource in medicine and health care. In the last 20 years the amount of available knowledge has grown at an extraordinary rate so that there are now more than 7000 identified disease entities and, for example, over 6000 operative procedures. Today's clinicians cannot hold it all in their heads but need to be able to draw on it at the click of a button. Similarly, today's citizens and patients have the expectation that the care they are getting is state of the art and embodies the latest knowledge and evidence.

Health professionals and policy makers across the world are responding to this challenge in a number of ways. The first and most obvious is that they are making sure that evidence is available in every clinical setting with access to data bases and research findings. For the most part, however, evidence and research findings need interpretation and translation for clinicians into practical ways of treating the patient in front of them. This has led to the adoption of three complementary and important approaches being adopted in developed countries around the world: the development of clinical guidelines or protocols for treatment; the study and understanding of variations in practice; and the systematic assessment of new therapies and treatments.

Portugal is in the process of developing clinical guidelines under the leadership of the Director General of Health and with involvement of the *Ordem dos Médicos*. Progress with these has temporarily been suspended due to disagreements about validation. Moreover, Portugal has not yet moved to the position of other European countries where the application of these guidelines is monitored and the reasons for any divergence understood. This has potentially very serious consequences. The Commission was told by patients' groups, for example, that there are more than 30 hospitals around the country undertaking breast surgery but that around a quarter of them did not have staff with the expertise to undertake the full range of treatments. They were not able to comply with existing guidelines, yet nothing was done about this serious lapse in quality. This is a topic addressed in Chapter 5 when dealing with the creation of specialist networks.

Knowledge is, and always was, a vital resource in medicine and health care. In the last 20 years the amount of available knowledge has grown at an extraordinary rate so that there are now more than 7000 identified disease entities and, for example, over 6000 operative procedures.

A forthcoming Portuguese study observes that there is considerable variation in the numbers of re-vascularisations and knee procedures undertaken in different parts of the country and questioned why this is.[18] Its observations are very similar to studies in other countries which show large variations in clinical practice. Some variation can be explained quite satisfactorily by differences in, for example, demography or the incidence of particular diseases in some areas or through lack of convincing evidence about best practice. Other variation may, however, have no satisfactory explanation and needs to be managed out of the system.

There is an exponential growth in the number of new Apps, devices and therapies around the world. Visitors to recent Telemedicine and eHealth conferences in India, for example, would have been able to inspect more than 100 different examples. Interestingly, very few would have been evaluated or the subject of objective research as to their benefits or failings. Citizens, countries and health purchasers and providers are faced with the dilemma of identifying the most effective and discarding the useless in an environment where new applications are entering the market at great speed.

Many countries now have processes for the assessment of new therapies and devices to understand not only whether they are safe – which is the responsibility of Infarmed and the European Medicines Agency but also how effective they are in comparison to other existing therapies and technologies. Not surprisingly, the companies which have developed and are selling the therapies wish to emphasise the advantages of their new product. Equally unsurprisingly, purchasers – most often governments on behalf of their national health systems – want independent evidence of their claims. Portugal does not currently have any consistent and system wide method for assessing new technologies, therapies and devices similar to the international example shown.

> The Commission's view is that the public should be able to expect that the treatments they receive are based on the latest and best evidence available globally and that any variations from this have good explanations.

The Commission's view is that the public should be able to expect that the treatments they receive are based on the latest and best evidence available globally and that any variations from this have good explanations. It believes that, as knowledge grows and becomes more publicly available, the use of clinical guidelines, the management of variations and the assessment of therapies will become ever more important. It has therefore concluded that the Government should set up a new independent agency – which it has called SNS Evidence – to bring together the development and dissemination of clinical guidelines and the assessment of new therapies in one body. This is the subject of a recommendation in Chapter 1. It would be responsible not only for developing guidelines and undertaking assessments but also for publicising the results to the public as well as to clinicians.

INTERNATIONAL EXAMPLE

The National Institute for Health and Care Excellence (England)

The National Institute for Health and Care Excellence (NICE) is a non-departmental public body of the Department of Health in the United Kingdom. It was set up in 1999, and has more recently taken on responsibility for social care following the Health and Social Care Act 2012. NICE carries out assessments of the most appropriate treatment regimes for different diseases, taking into account both desired medical outcomes and the economic efficiency of different treatments.

NICE's role is to improve outcomes for people using the NHS and other public health and social care services by:

- Producing evidence-based guidance and advice for health, public health and social care practitioners;
- Developing quality standards and performance metrics for those providing and commissioning health, public health and social care services;
- Providing a range of information services for commissioners, practitioners and managers across the spectrum of health and social care.[19]

NICE publishes guidelines in four areas: health technologies within the NHS (such as the use of new and existing medicines, treatments and procedures), clinical practice (guidance on the appropriate treatment and care of people with specific diseases and conditions), guidance for public sector workers on health promotion and ill-health avoidance, and guidance for social care services and users.

This evidence-based guidance and advice takes several forms. **Clinical guidelines** provide the NHS and others with advice on the management of individual conditions. They are systematically-developed statements to assist professional and patient decisions about appropriate care for specific clinical circumstances. They are developed in association with the Royal Medical, Nursing and Midwifery Colleges. **Technology appraisals** assess the clinical and cost effectiveness of health technologies, such as new pharmaceutical and biopharmaceutical products, but also include procedures, devices and diagnostic agents.

Interventional procedures guidance recommends whether interventional procedures, such as laser treatments for eye problems or deep brain stimulation for chronic pain, are effective and safe enough for use in the NHS. **Public health guidance** covers disease prevention, health improvement and health protection and has influenced policy and practice in the NHS and local government on many of the big issues in today's society such as smoking, obesity, physical exercise, alcohol misuse and accident prevention.[19]

NICE has a transparent consultation process throughout the development of our guidance and quality standards which allows individuals, patient groups, charities and industry to comment on our recommendations. This includes a Citizens Council, the UK's first advisory body made up entirely of members of the public from across the UK.

NICE is internationally recognised for the way it develops its recommendations, a rigorous process that uses the best available evidence and includes the views of experts, patients and carers, and industry.

SCIENCE AND TECHNOLOGY

Science and technology are rapidly changing the world: from advances in biology to information and communication technologies to micro-engineering and nanotechnology. The Commission has not attempted to review the current position in Portugal or globally on the developments of bio-medical science, but it does fully recognise the major impacts they will have in the years to come. Some of these technologies will help predict and prevent disease as well as assist with improved "personalised" therapies and health care. They could have the potential to extend healthy life enormously. They are also very likely to bring extra costs – discussion in Chapter 7 shows that technology has been one of the main drivers of cost globally in health care in recent years. Additionally, as noted above, this explosion of developments present challenges in sorting out the useful from the useless.

The Commission's Working Group 4 on "Harnessing knowledge, technology and innovation" reviewed this area and concentrated on three aspects where it felt there was most to gain in the short term and which would position Portugal to the best advantage for the longer term. These are the development of an electronic health record as the foundation from which both patients and clinicians could operate most effectively; the use of mobile devices to monitor and provide advice to patients in their own homes and communities; and the development and introduction of new and more flexible regulatory frameworks for new devices and therapies.

The second area – the use of mobile devices – has already been touched on in Chapter 2 in the discussion of shared care and will be returned to in Chapter 5 where services are discussed. The Commission commends consideration of the third area – the creation of more flexible regulatory frameworks to the Government. This is a very important issue. Excess regulation can be very time consuming and costly, and inhibit innovation. Current Portuguese and European systems were developed for a time when developments were less rapid and fewer organisations involved in the field. There is undoubtedly scope for speeding these up particularly where collaboration between private industry and public bodies which will allow both for better targeting of developments on areas of the greatest need and ensure there is greater openness in sharing and scrutinising the results of trials.

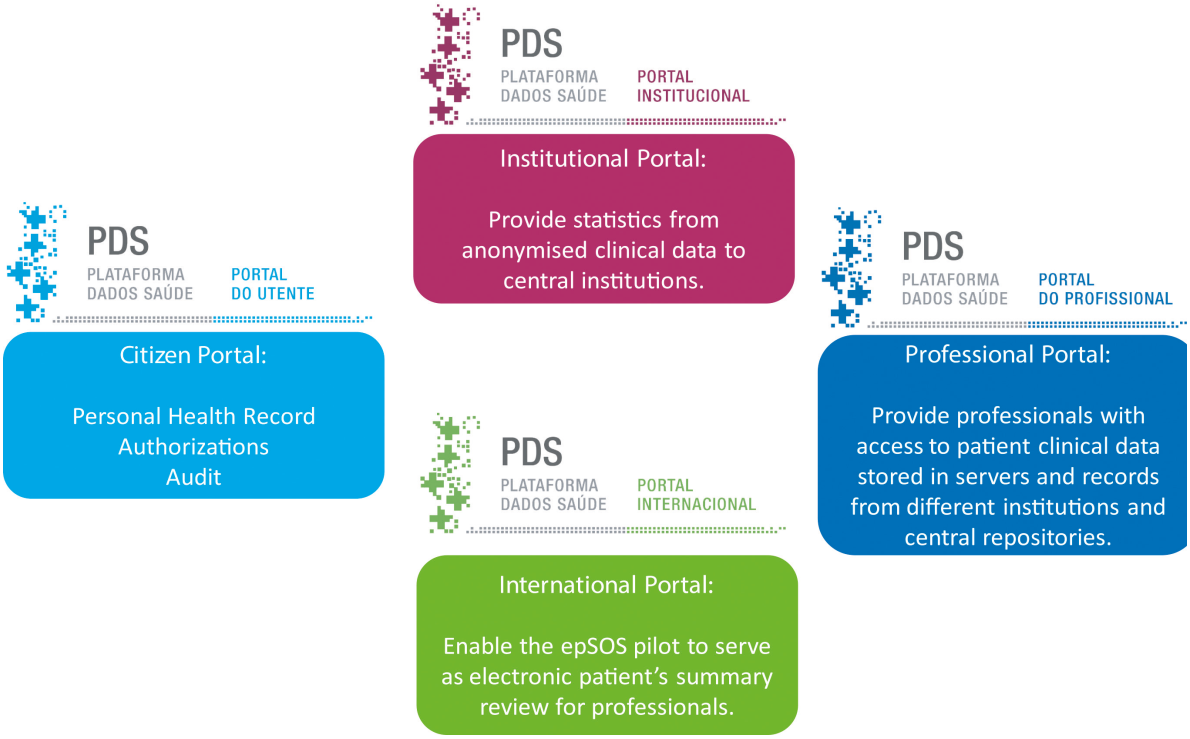
THE ELECTRONIC HEALTH RECORD

The electronic health record is core to improved quality of care, the spread of knowledge and the development and use of other technologies. A patient's electronic health record is an integrated record of all their health-related data – an account of their diverse encounters with the health system as recorded in patient or medical records maintained by various providers including GPs, specialists, hospitals, laboratories and pharmacies.

Electronic health records allow different healthcare professionals to get a rapid view of the patient's entire medical history, and see how existing treatments might interact with ones they are considering. They reduce paperwork, freeing doctors and nurses to spend more time with patients, and can improve data gathering to improve care and knowledge. They are essential for an efficient, integrated healthcare system.[20] They also allow patients to maintain an overview of their own health history and, to the extent that they want to, understand their treatments, share information with family and carers and manage their own care to best effect.

Working Group 4 explored the creation and implementation of a standard electronic health record in Portugal. It found there to be a great need for an integrated and universal record – the current situation is that data is unusable

Figure 3 · **The Portuguese Electronic Health Record**[21]



Institutional Portal:

Provide statistics from anonymised clinical data to central institutions.

Citizen Portal:

Personal Health Record
Authorizations
Audit

Professional Portal:

Provide professionals with access to patient clinical data stored in servers and records from different institutions and central repositories.

International Portal:

Enable the epSOS pilot to serve as electronic patient's summary review for professionals.

across systems, records are not accessible, and data needed in emergency situations is lost due to lack of storage. It also found that Portugal was very well placed to implement a universal electronic record, having much of the infrastructure in place and a sound policy framework.

A summary of progress undertaken as part of the OECD review of quality in June 2014 showed that developments were being undertaken on the basis of clear principles – such as the need to build on the "legacy" systems of the past; the importance of a shared entry point for all professionals; the customisation of data to suit different departments and professions; and links to protocols and registration systems.

The central role envisaged for the Portuguese electronic health record, shown in Figure 3, illustrates how it can provide customised access for citizens, health professionals, data collection for institutions and offer an international perspective.

The Working Group concluded that Portugal could play a leading role in developing and defining standards for interoperability and use across Europe and proposed the *Lisbon Doctrine* as a basis to take this forward. The Commission very much supports the introduction of an electronic health record and recognises the importance of implementing this in a way that is compatible with Portugal's neighbours, given both the new arrangements for health care across boundaries and the importance of sharing learning and developments internationally. The Working Group also strongly recommended that citizens should have ownership of their own records.

The Commission has already taken this up in Chapter 2 in the discussion of the role of citizens. It has recommended that enhanced priority is given to the creation of the electronic record and that citizens should own their own information both within the electronic system and more generally. It also commends the idea of the *Lisbon Doctrine* to the Government.

There is a great deal of room for sharing experience and learning between countries as well as for joint protocols for development. The Danish experience, described below, offers another example of a national record.

INTERNATIONAL EXAMPLE

Denmark – Electronic Health Record

Sundhed.dk is an eHealth portal established between all public health authorities in Denmark. The portal was launched in 2003, and is part of the common infrastructure in the healthcare sector in Denmark. Citizens can gain access to general and personal information and professionals have access to a number of services and their record.

The Ministry of the Interior and Health and its various agencies remain the authority in decision-making in relation to national standards and infrastructure. Regions and municipalities are in charge of managing their own projects and observing the framework and requirements laid down at the national level.

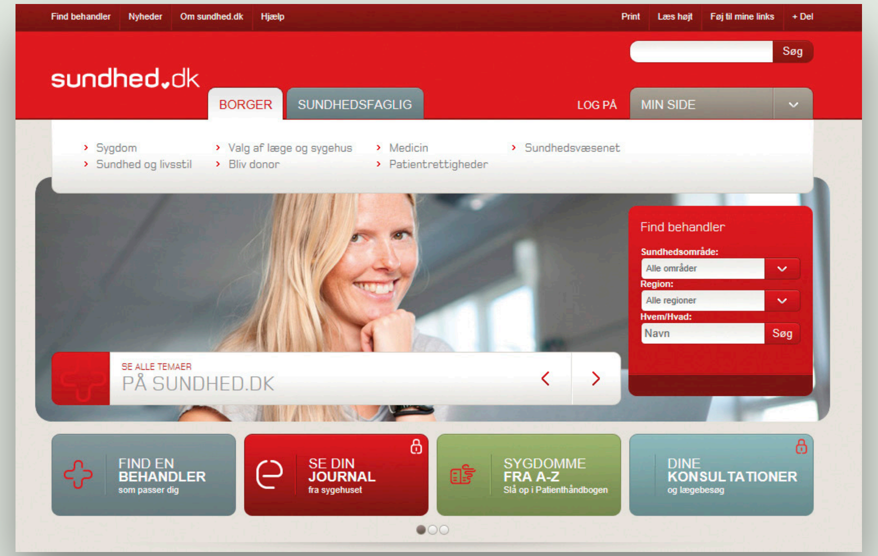
Denmark has a common infrastructure in the form of the National Patient Registry (DNRP), which has served as a data set of hospital contacts since 1977. This is a unique registry featuring long-term comprehensive documentation, on the level of the individual.

The service called "My Health summary" is available through the Danish eHealth portal 'Sundhed.dk' for citizens and allows authenticated users to obtain a faster and better overview of their own patient data. Once logged into the health portal with their digital signature, users can access personal health information that has been gathered from various healthcare sources.

Denmark is known as a global leader in electronic health records. Its success is attributed to a number of factors: [22]

- A unique personal identifier is issued to all Danish citizens at birth and a digital signature is widely used
- National Health Databases maintained for more than 30 years
- IT-ready population: Broadband penetration is the among the highest in Europe – 95% of the population have internet access
- Legal revisions in recent years have established a broader access to personal health data for medical staff
- Denmark's population is only 5.5 million, making it easier to implement the technology
- Rapid clinical acceptance of EMRs, which were developed in close consultation with physicians to ensure their utility, rather than imposed from above
- The government also provided financial incentives – cost is another frequent barrier to acceptance – as well as paying for technical support, including sending data-consulting teams to medical practices.

All Danish primary care physicians act as healthcare gatekeepers and co-coordinators for their patients, and use one of a number of interoperable electronic medical record (EMR) systems. These allow doctors to make their own notes, but also act as a central repository for information relayed from outside the physician's office. Patients can see select data from both



EMRs and hospital records via the national health portal (sundhed.dk) and more recently through Denmark's citizen's portal (borger.dk). On these sites they can also contact, or even change, doctors.[23] Use of EMRs has greatly increased efficiency, saving primary care doctors an average of 50 minutes per day through reduced paperwork and faster communication. In work terms, this allows them to see 10% more patients.[23]

The system generates automated preventative health reminders and warns prescribers about potential harmful interactions with existing prescriptions. More rapid receipt of important data (the average time for receipt of hospital discharge summaries has dropped from four weeks to less than two days) is another important advantage.

Beyond such obvious applications, the power of the data in these systems is also being harnessed to improve clinical outcomes for certain chronic diseases. Every medical practice can see how its own patients fare compared with regional and national norms. This allows easy identification of those with suboptimal treatment, and indicates areas needing improvement. The database is also starting to be used for research purposes to examine best practice.

Denmark does not actually have a single national medical-data system – the key has been creating systems that work together. Medcom, a government-financed cooperative venture, has acted as a data integrator ensuring interoperability.

TELEMEDICINE, eHEALTH AND mHEALTH

Portugal's plans for the electronic health record involve the use of telemedicine and eHealth and mHealth as modalities for gathering and sharing information. It, together with the record itself, will play a particularly important part in the development of specialist networks described in Chapter 5.

A recent study, published by the Calouste Gulbenkian Foundation, reviewed the current state of telemedicine in Portugal.[24] It described existing networks such as the paediatric cardiology network based on Coimbra and revealed both the potential and the difficulties of future development. The Commission will not attempt to repeat or reprise this comprehensive and important work here. It notes that the study's conclusions are for the development of a strategic approach to future development – building on the piece meal development that has been led by pioneers in the field – and the creation of the right cultural, professional, physical, policy and financial environment to allow telemedicine to achieve its potential benefits. Can we check if this also highlights the importance of access for citizens and patients.

PARTNERSHIPS AND SUPPORT FOR INNOVATION

It should be emphasized that biomedical research in Portugal has made most remarkable progress in the last decade due to an intensive intervention in scientific education, namely through international PhD programs, and the creation of the so-called "Associated Laboratories" of the Ministry of Science. Yet the articulation between basic and applied research and the fostering of more effective "translation medicine" still lags behind, and the universal decline of the so-called "physician-scientist" may affect the cooperation between scientists and clinicians. In addition, closer attention should be paid to the development of research programs within the health care units, particularly in clinical and public health domains. Furthermore, as this report has amply demonstrated, epidemiological and socio economic research are critical in the proper design and implementation of all health care policies. All this should be furthered developed through partnerships across the public and private sectors amongst other means.

The vision described in this report depends on redesign and innovation, drawing on the creativity and skills of all parts of the population and sectors of society. Industry, academia and the SNS all have particular strengths in research and development on new therapies and devices which can support health as well as health care. As Working Group 4 told the Commission, the implementation of mobile devices to support health care in a non-hospital context will not only:

> *"Improve the citizens' quality of life and upgrade the performance of the National Health System … both for prevention and care delivery support". It will also "Make use of the best knowledge in medical sciences and of technology for health (particularly: ICT, nanotechnology, and materials), and should result in a marked reduction in health costs."*

The group also argued that the Portuguese industry could play its part in development leading to "*Improvements in health, adequate and timely access by patients to more sophisticated medical care, promote the economy, creating new businesses and expanding the existent ones, creating jobs for the new generation of highly skilled workers*".

The Portuguese health industry sector is well organised through Health Cluster Portugal. It was established in 2008 as a private, not-for-profit organisation with the aim:

"to turn Portugal into a competitive player in the research, design, development, manufacturing and commercialisation of health-related products and services, in selected market and technological niches, targeting the most demanding and relevant international markets, based on the recognition of its excellence, technological level and competences in the field of innovation". [25]

The cluster is made up of more than 120 entities, including hospitals, companies, and scientific and technological institutions. Its current areas of strategic interest include health and active aging, personalised medicine, health tourism and e-health.

The Health Cluster has proposed to the Commission that greater collaboration can be achieved through:

- Fostering the participation of Portuguese universities and hospitals, in collaboration with each other and with companies, in national (e.g. Portugal 2020) and transnational (e.g. Horizon 2020) R&D projects, in selected specialisation areas. This line of action includes, for example: i) identifying and disseminating calls and partnership opportunities; ii) supporting the formation of consortia and the application processes; iii) assisting the public authorities/agencies in the definition and implementation of incentive schemes for companies to hire PhD graduates – as a mean of favouring a better interaction between universities/hospitals and companies and, therefore, the promotion of collaborative projects among them.
- Promoting: initiatives to make the universities' and hospitals' research infrastructures, expertise and technologies more accessible to external researchers and companies, thereby boosting knowledge/technology

transfer, as well as the contracting of R&D services and clinical trials by companies. This includes nurturing initiatives such as the Translational and Clinical Research Infrastructures Specialisation Platform – Health Cluster Portugal (TRIS-HCP), as well as integrating Portuguese universities and hospitals in European technology platforms and research infrastructures consortia (e.g., EATRIS ERIC).

- Improving the levels of qualification and training of human resources/teams working in Portuguese universities and hospitals, in terms of translational and clinical research project management, as well as in the management of innovation, intellectual property, technology transfer and entrepreneurship.

The Commission believes that it is important for Portugal to take up the opportunities that these sorts of action present. These need to be done within the framework of the public/private concordat, proposed in Chapter 5, so that this is done on the basis of shared vision, shared values and shared principles. Moreover, the Commission believes that there is scope to bring together industry, academia and the SNS in a small number of centres to foster collaboration around specific high priority goals such as, for example, the development of home monitoring or the development of young children or the needs of people with dementia. They could also address collaboratively the case for more flexible regulation of new products mentioned earlier. The Academic Health Sciences Centres and Networks in England provide one model that could be considered.

INTERNATIONAL EXAMPLE

Academic Health Science Centres and Networks in England

Academic Health Science Centres (AHSCs) and Networks are partnerships between universities, industry and healthcare providers, which work collaboratively on research, education, training and services, with the aim of translating research into practice, with breakthroughs leading to direct clinical benefits for patients. AHSCs were set up in the UK in 2007, and there are now seven in operation, with more planned. The intention is that AHSCs should address problems of access, unreliable quality and high cost, by not only developing new drugs, devices, and other technologies, but also new ways of deploying broad, inexpensive preventive and treatment strategies among populations.[26]

There is also scope for enhanced partnerships between the SNS and universities in research and development. The following example from France shows how universities and hospitals are collaborating to target drugs at specific tumours. It also shows the advantage of having a specialist network in as a means of improving treatment and development.

INTERNATIONAL EXAMPLE

Cancer therapies in France

In 2005, the French government agreed to pay for the treatment of every citizen shown to be likely to benefit from targeted drugs. The National Cancer Institute established research facilities at university hospitals and cancer centres, where biopsies of cancerous tissue from patients all over France are sent for genetic testing. If the tissue sample indicates that the patient should respond to the drugs, they are treated with them. Targeted drugs now account for 57% of France's cancer-treatment budget.

According to analysts, this model seems to work. *"The French platforms have so far tested samples from around 15,000 people with lung cancer for alterations in the EGFR pathway. Just over 1,700 patients tested positive and were given the drug until they stopped responding (an average of 38 weeks). That has cost France 35 million euros. Had all 15,000 patients been given an eight-week course of the drug just to see whether they would respond, it would have cost the nation another 69 million Euros — with no extra benefit."* [27]

CONCLUSIONS AND RECOMMENDATIONS

The four strands identified at the beginning of this chapter are designed to help Portugal position itself to take full advantage of future advances in science and technology. The Commission has already made recommendation in Chapters 1 and 2 about:

- The establishment of SNS Evidence as a new agency, which brings together the existing programme of clinical guidelines with a new process for assessing new technologies and therapies, and ensures that evidence is available everywhere within the system at all times. The agency should make its deliberations and findings open to the public so that they as well as clinicians are able to see and understand the evidence.
- Giving high priority to implementing fully the Electronic Health Record as the essential underpinning of an integrated and high quality service and giving citizens ownership about all the information held about themselves whether in an electronic form or otherwise.

In this chapter it makes further recommendations about:

- Continuous quality improvement where, as described in Chapter 1, there is a need for a new expert agency to identify and spread good practice and support implementation.
- Effective collaborations between the SNS, the research community, citizens and industry.

Together, these interventions will help to create a learning environment in Portugal where continuous improvement will become normal practice.

Figure 4 · **Recommendations**

RECOMMENDATIONS

12. **CONTINUOUS QUALITY IMPROVEMENT.** All partners in the health system from the Ministry and citizens to SNS bodies, municipalities, universities and industry need to ensure that the approach of continuous quality improvement is adopted throughout the system as a means both of promoting quality and of ensuring that new scientific and technological advances can be systematically integrated and implemented everywhere. Expertise in quality improvement needs to become part of every health worker's education and training. This should be supported by a new expert agency able to promote quality improvement, identify and spread good practice and support implementation. It should work with health and other bodies to create and confirm shared methodologies for quality improvement and implementation; facilitate training and be able to offer advice and support as necessary. This needs to be accompanied by standardisation of accreditation processes and of data collection and reporting.

13. **SNS COLLABORATIONS WITH RESEARCH AND INDUSTRY.** SNS, research and industry leaders should set up collaborations in a small number of locations around the country to work together and with citizens on developing new practices, technologies and services.

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A person-centred and team-based health system

5

The health system must become more person-centred and team based. New service models are needed which provide integrated care for all individuals with particular emphasis on: chronic disease management; the development of more services in the home and local community; and the creation of specialist networks – based in reference centres but reaching all parts of the country through technology and shared protocols.

INTEGRATED CARE FOR EACH INDIVIDUAL

Integration of services and the personalisation of care are themes running throughout this report. They are becoming ever more important as the population ages and more people suffer from chronic diseases and co-morbidities. It is essential that every individual's care is well planned and coordinated and not fragmented and inconsistent. This chapter addresses how truly integrated and person centred care can be developed through three main sets of strategic actions:

- The creation of new service models
- Redesign of the health system
- Partnership in planning and service provision

THE HEALTH SYSTEM

Portugal, in common with other Western European countries, began the development of state social security measures in the late 1940s; although it was not till 1971 that the Government assumed responsibility for providing healthcare services to the population. The SNS was established as a universal, tax financed system in 1979. A history of this development provided by Working Group 1 is reproduced in Appendix 6.

The government may act to achieve this either by the direct provision of health services through the SNS or through contracting with private providers. According to Article 64 of the Portuguese Constitution, health policies should promote equality of access to healthcare for the citizens, irrespective of economic condition and geographic location, and should ensure equity in the distribution of resources and use of healthcare services.[1] Immigrants have the same access to healthcare as Portuguese citizens and the SNS cannot refuse treatment based on nationality, illegal immigrant status or lack of financial means.

Over recent years, the European Union has begun to have greater influence over Portuguese health policy with, for example, the European Working Time Directive (affecting the hours that staff may work),[2] Competition Policy,[3] regulations on procurement[4] and, more recently, the directive on the cross border flow of goods and services.[5] This influence can be expected to grow over time. Portugal has also maintained close links with the European Region of the WHO and stayed broadly in line with developments and trends for policy and service delivery across Europe.

Against this background, Portuguese people have access to a wide range of services from health promotion advice to the highest levels of specialist treatment. They are required to register with a GP in their place of residence or employment and their first point of contact, except in an emergency, is expected to be with their local primary care service. Primary care offers many local services including general medical care, reproductive and child health and the provision of immunisation and health advice, but also plays a "gate keeping" role by managing referrals to specialist care. Since 2007, citizens have also had access to a telephone help line, *Saúde 24*.

> Portuguese people have access to a wide range of services from health promotion advice to the highest levels of specialist treatment.

Patients can use primary care, ambulatory care and diagnostic services provided by SNS units; by private for-profit and not-for-profit groups and individuals; or by groups of professionals working under contract to the SNS. SNS provision of dental care is limited with few dental care professionals, so people normally use the private sector. Most prescriptions have to be filled at community pharmacies although hospital pharmacies have recently been opened and allowed to dispense. Non-prescription or over the counter medicines are now available in a number of specialised stores as well as in pharmacies, and prices are no longer fixed.

Specialist secondary and tertiary services are mainly provided in Portugal's 189 hospitals, 77 of which are SNS ones, with non-emergency access generally provided by referral from primary care. Most of the bigger and more specialised hospitals are SNS ones, with the private sector, including the not-for-profit *misericórdias*, providing smaller units. Mental health is based around local mental health services with multidisciplinary mental health teams, ambulatory services in primary care and inpatient and emergency services provided in hospitals. This service is still, however, very hospital dominated with recent strategies seeking to reverse this position. Here again, services are provided by a mix of public and private providers.

Mainland Portugal has an integrated medical emergency service coordinated by INEM (*Instituto Nacional de Emergência Médica*), an indirectly managed part of the Ministry of Health. It has the responsibility to respond to emergency calls via the 112 telephone number, provide first aid at the scene, assist with transportation to the appropriate hospital and ensure coordination between all the participants in the system. The service is provided free of charge and, following full roll out of the coordinating centre CODU across the country between 2004 and 2008, there have been large increases in calls to the centre and journeys made by ambulances.

These changes to the emergency services are amongst the many reforms and initiatives over recent years designed to improve and expand services. Four of the major ones have dealt with primary care, public health, continuing and long-term care, and hospitals respectively.

Primary care has been patchy and inconsistent in quality, resourcing and distribution. Many citizens don't have a family doctor in reality. Even where they are registered with a family doctor, many go by preference directly to their local hospital's emergency department when they perceive a need, rather than going to or via their primary care service. The result is that an estimated 25% of attendees at emergency departments do not need immediate treatment.[6] International comparisons show that attendances in emergency departments in Portugal are proportionately twice as high as in England and 50% higher than in France.

> Even where they are registered with a family doctor, many go by preference directly to their local hospital's emergency department when they perceive a need, rather than going to or via their primary care service. The result is that an estimated 25% of attendees at emergency departments do not need immediate treatment.

In response to these problems, the Ministry established new administrative and delivery structures and created a Task Force for Primary Healthcare in 2006 to guide the overall development of the service. At the most local level primary care services have been grouped into family health units (*Unidades de Saúde Familiar,* USF) which bring together 6-8 family doctors, with a similar number of nurses and a small group of other staff to deliver services for a population of between

4,000 and 14,000. USF have been given a degree of autonomy and are funded through a contract that rewards productivity, accessibility and quality.

At the next level, 75 Health Centre Groups (*Agrupamentos de Centros de Saúde*, ACES) provide direction, coordination and support to primary and community services. They are responsible for ensuring that services are available to area populations, which range in size from about 50,000 to about 200,000 people. They have also taken on responsibility for integrating public health into the wider healthcare system.

Doctors were given choice over whether or not to join these new structures and to enter into the new contract. The result was that about half the country is covered by them, with the rest continuing as before to provide services from individual or group practices of varying quality and capacity and without the new reward structure.

Public health had problems of both image and capacity. The 2004 National Plan set out to strengthen it, provide better linkages into health services and give public health doctors a wider role in terms of the health of the population. Local public health structures now fall under the remit of ACES, alongside primary and ambulatory care, whilst maintaining their links centrally to the Directorate General of Health and the nationally run programmes of health education, promotion and protection. The need to strengthen public health to a far greater extent was discussed in Chapter 3.

The provision of long-term care in Portugal has traditionally been the responsibility of families and charities whilst public provision has played only a minor role.[7] This is reflected in the relatively low levels of provision of long-term care in the country. In 2011 only 1% of the population aged over 65 was receiving care in institutions and a further 0.4% received care at home. These figures are very much below the OECD averages of 4% receiving institutional and 7.9% receiving home care. At that time Portugal was spending about 0.1% of its GDP on long-term care, well below the OECD average of 1.6%.[8] Palliative care is still relatively underdeveloped and provided by charities with some government support. Larger municipalities employ social workers with part funding from the Ministry of Social Security.

The National Network for Integrated Continuing Care (*Rede Nacional de Cuidados Continuados Integrados*, RNCCI) was created in 2006 to develop this neglected area and coordinate the various providers of care in hospitals, local authorities, *misericórdias* and the private sector within local networks. This is described in the following example.

PORTUGUESE EXAMPLE

The National Network for Integrated Continuous Care (*Rede Nacional de Cuidados Continuados Integrados* – RNCCI)

The network provides short-term rehabilitation, as well as long-term and palliative care, with multi-disciplinary professional teams working in the community as well as in health centres and hospitals. Partnerships are established between the public, third and private sectors in models of cooperation and shared financing.

- Centrally managed and monitored, with regional and local teams which coordinate services and implement policies at these levels
- Provides multidisciplinary care assessment for people in need of post-acute and long-term care
- Organises referrals between the hospital discharge teams and community and domiciliary care
- Use of an online data management system aims to provide continuous needs assessment and ongoing monitoring of care recipients with benchmarking of results [8]
- Local coordination teams establish quality and safety standards for facilities and staffing
- Financial model developed for inter-sectoral financial resource distribution – budgeting based on programmes transfers focus from resources to results.

Whilst the national programme ceased in 2012, the local networks continue to provide convalescent care, medium-term care and rehabilitation, palliative care and day care. New protocols and partnerships were developed and the number of beds provided in this way grew from 3,173 in 2007 to 5,900 in 2012. [9]

Hospitals have relatively long waiting lists for some elective surgical procedures and have large numbers of beds occupied by patients in need of continuing care. The development of the RNCCI network has been designed partly to help with this, but there have also been reforms to the hospital sector. These have included giving greater autonomy to SNS hospitals and creating an effective provider-purchaser split. Most SNS hospitals are now structured as Public Enterprises (*Hospitais EPE*), with a smaller number as Public Companies (*Hospitais SPA*), and receive their funding through an annual-contracting process. Nine units have also taken on responsibility for both health and care services, working across the boundary between primary and secondary care.[7]

At the same time, Portugal has developed private-public partnerships, with 6 new hospitals recently opened or under construction. The private sector has also opened 3 large hospitals in the Lisbon district alone, and begun to compete on a greater scale with the SNS.

There is no standardised method for collecting and analysing patient satisfaction ratings although some studies have been done. The results are very mixed. The European Observatory Report outlined that Portuguese people are quite happy with primary care provision:

> *"Over 70% of the respondents were very satisfied with their physician and their involvement in the decision-making process regarding their own health. However, some issues arise about the organization of services, as more than 55% of the respondents identified excessive waiting times and difficulty communicating with the GP."*

However, the Deloitte consumer survey from 2011[10] reported that:

> *"Satisfaction overall is low: 13% of consumers are satisfied with the performance of the health care system; 22% are not at all satisfied. Consumers are dissatisfied with wait times (70%), access (39%), and failure to focus on patient-centered care (37%) and wellness (34%). Consumers are satisfied with modern technology (41%), innovation (40%), and facilities (29%)."*

NEW SERVICE MODELS

Portugal has taken many steps towards integrating services with, for example, the promotion of primary care as the place to integrate a person's needs; the establishment of the nine integrated acute and community units which can deploy staff and funding across hospital and community boundaries; and the creation of the *Via Verde* protocols for coronary heart disease and strokes which are designed to manage care across organisational boundaries and secure rapid and evidence based treatment for each patient. The establishment of *Saúde 24* and the *Portal da Saúde* both complement this approach.

A recent report highlighted the importance of integration and made the very important point that there are several elements to take into account here including: the clinical dimension; financial incentives; administrative issues; and systems issues such as the creation of structures for integration and reinforcing a culture of organisational integration.[11]

Many of these pieces need to be put in place in Portugal and other countries. Financial systems in western countries, for example, generally incentivise action within organisational

Financial systems in western countries, for example, generally incentivise action within organisational boundaries rather than across them. Portugal is no exception.

boundaries rather than across them. Portugal is no exception. Moreover, several of the changes made to promote greater integration have not yet been fully followed through or evaluated. The primary care changes only cover half the country, for example; the *Via Verde* is only used for about 30-40% of patients; and the integrated hospital and community services have not been evaluated.

The next few pages discuss the sort of new service needed for the future and illustrate it with a few examples of what is already being done and can help bring the future to life. Self-care and shared care were addressed in Chapter 2. This chapter deals in turn with:

- Chronic disease management
- Developments in the community and home including primary care, long-term and palliative care
- Mental health
- Acute and specialist services

CHRONIC DISEASE MANAGEMENT

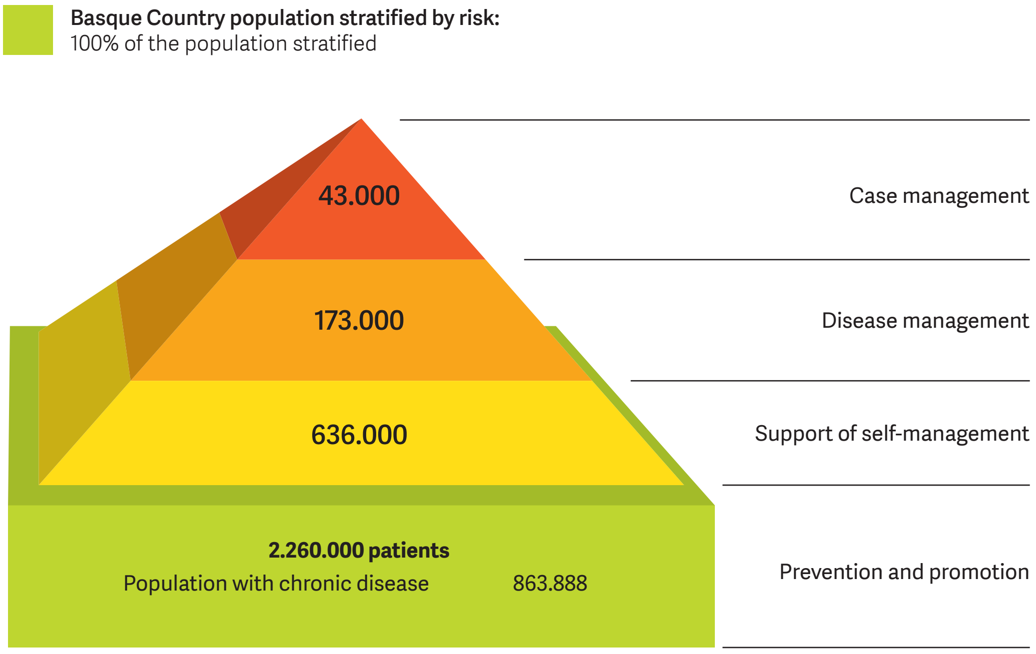
The growth in chronic diseases and the attendant impact on people's lives and societal costs has already been described in Chapter 2. Three points stand out: the number of people with chronic diseases is already estimated at 5.4 million and growing fast as the population ages; there are high levels of obesity amongst children which pre-dispose them to ill health in later life; and many Portuguese people spend longer periods of their lives in ill health than their contemporaries in Western Europe.

Reducing these high levels of morbidity must be a priority for Portugal, not only to improve people's lives but also, as the Commission will argue in Chapter 7, as one of the main ways to achieve a financially sustainable health system.

Internationally, many countries have developed quite sophisticated methods to segment the population in terms of their risk of needing care from the health system and to create different ways of dealing with each segment. Figure 1 below is from the Basque country and shows how the Government has created a "*Kaiser Pyramid*"– named for Kaiser Permanente where this approach was developed – to show how many people there are in each of four segments of the population and to plan how to serve them. The small top group are mostly people with complex and multiple chronic diseases who need attention from their own case manager; the second larger group mostly have one or two diseases and can be looked after by the appropriate specialities in liaison with primary care; the third and fourth much larger groups are provided with support for self-management and health promotion and disease prevention services.

These segments can also be correlated with anticipated costs to the system. Thus, for example, in many western countries, around 5% of the population (in this example the top group and some of the second one) use about 40% of health care resources, whilst 10% (the top two groups here) use about 70%. Recent analysis from the north of England suggests that when the costs to the whole health and care system are taken into account, in other words including the costs of residential care not covered by the health budget, about 3% of the population use about 2/3 of the total budget.

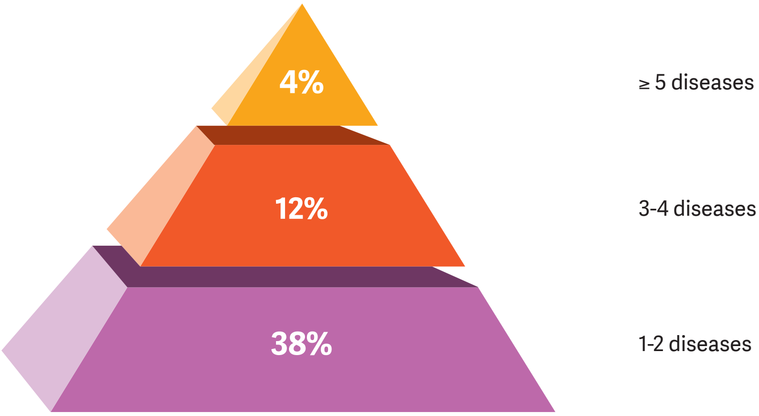
Figure 1 · **Chronic disease management in the Basque Country**[12]



Dr. Luís Campos has undertaken a similar analysis in Portugal based on figures from the National Health Survey 2005-2006. He has estimated the proportions of the population with one or more chronic diseases as shown in Figure 2. This would mean that 5.4 million people suffer from at least one chronic disease in Portugal. He has been unable to estimate the full costs of this but has calculated that the 5% of longest stayers in Portuguese hospitals use 31% of the bed days.[13]

Figure 2 · **Percentages of the Portuguese population with one or more chronic diseases**

Kaiser Permanente pyramid illustrating health care needs of the Portuguese population with one or more chronic diseases (INS 2005-2006)



© Luís Campos

These analyses show the importance of creating the best service models to deal with chronic diseases both in term of improving the quality of care for the patient and managing costs within the system. The lessons from figure 1 are twofold: the importance of providing the right sort of service for each group of patients and, secondly, and as importantly, the importance of prevention and promotion to keep people as near to the bottom of the pyramid as possible.

COMMUNITY, HOME AND PRIMARY CARE

The next 25 years will see a major transition from a hospital based service to one where most care is provided in the community – often in a shared care arrangement between individuals and their clinicians. It is a future in which care will mostly be delivered to the patient where they are, rather than the patient having to go to a distant, and often very busy, hospital to find it. The science and the technology described in Chapter 4 will have a very large part in helping this to develop.

National and international policy is all moving in this direction for reasons of both quality and cost. All the Commission's Working Groups advocated this approach with Working Group 4 pointing out the scope for:

> *"the wide uptake of mobile devices in a non-hospital environment, both for prevention and care delivery support."*

Whilst Working Group 1 recommended that primary care should be at the heart of the whole system:

> *"Every citizen or family has the opportunity to access a Primary Health Care team at local level. This team has the aim of coordinate the management of people's health needs".*

As described earlier, there has been improvement in primary care in recent years with a new structure in place. However, the Commission was repeatedly told about problems with primary care and, as described earlier, the public tends to use hospitals in preference to primary care. There were concerns about funding and staffing, about communication between primary and secondary care and about public attitudes. These are very big problems for a service that is expected to be the bedrock of the whole system in the future.

Primary care in Portugal has not had the investment and development over the years that have gone into other European systems. In England, for example, GPs earn as much as hospital doctors and have incentives to take on services previously delivered in hospitals. They have also been given the budget by the Government to buy hospital services for their patients and are now truly playing the leading role in the system.

As the transition from hospital based to community based services continues primary care in other countries is coming under increased pressure and traditional models based on a small number of GPs in a practice are beginning to look outdated. A recent study by the Kings Fund and Nuffield Trust found that no one organisational model is appropriate for all situations but proposed instead a set of design principles for the future.[14] It concluded that the future of primary care was likely to be in a diverse set of units linked together into federations, networks or merged partnerships in order to increase their scale, scope and organisational capacity. This approach is mirrored in other countries such as New Zealand, the Netherlands, Canada and the United States.[14]

Portugal's Health Centre Groups (*Agrupamentos de Centros de Saúde*, ACES) are in many ways a good example of this. They are designed to provide direction, coordination and support to primary and community services and, therefore, seem well suited to playing this role. These were rolled out on a voluntary basis and have only been established across half the country. Given the scale of the problems and the importance that is attached to creating new community, home and primary services, there is a clear need to roll out these arrangements across the whole country.

However, the Commission also judges that there is a need for a flow of new ideas and innovations in an area where technology has not yet really been exploited and where there appear to be fairly rigid staffing structures and practices. It suggests that this is an area where there should be more diversity and experimentation. This might include support for new staff grades such as the family nurse referred to in chapter 6; greater links with an emphasis on public health in primary and community services; innovative home monitoring and treatment; partnerships between the different sectors and with non-governmental and private groups; and the further development of models for linking acute and community services.

The Commission believes that Portugal could usefully consider the "assets based" approach that is becoming popular in a number of countries. This involves health and care workers using the assets available to them in the community to provide care and promote health and well-being.[15] It is not a new idea, people in resource poor settings have always improvised and innovated in this way, but has become of increased interest in the West as resources have become more constrained.[16, 17] This "assets based" approach is a very good example of the cross-sectoral working advocated in Chapter 3. Everyone has a role to play in improving health and health care.

Primary care in Portugal has not had the investment and development over the years that have gone into other European systems.

The Commission recognises the excellent example of ministries, the SNS and municipalities working together in creating the National Network for Integrated Continuous Care in 2006 described earlier. It is an example of joint working but it also illustrates the efforts that increasingly need to be made to enable people to retain their independence as they become increasingly incapacitated by disability and age. This will undoubtedly be a priority area for investment in the future as and when funding becomes available.

Palliative care requires development globally and was the subject of a World Health Assembly resolution in 2014. In Portugal, as in other countries, it has largely been developed through the efforts of individuals with a passion for the discipline, and now needs further development. There is recent research both about the level of need for palliative care[18] and about how palliative care can be delivered by non-specialist staff within hospitals.[19]

Recent research has shown that in Portugal 25-40% of people admitted to hospital die within a year and that 60% of deaths are in acute hospitals despite many people's wishes to die at home.[20] There is therefore a need to develop this service within the community. The following example shows how this is being done in one centre in the north with learning being spread elsewhere in the country.

PORTUGUESE EXAMPLE

Palliative care in Trás-os-Montes

Since 2009, the Calouste Gulbenkian Foundation has supported a pilot home-based palliative care in the Planalto Mirandês, in Trás-os-Montes. From village to village, a doctor, nurses and other health professionals help scores of patients of various ages, social conditions and family circumstances, pass the end of their lives in the most appropriate way.

This development has been extended to support the creation of 6 domiciliary Palliative Care Units (UDCP), in rural and urban areas in the north and south, and its operability, in partnership with local entities (Holy House of Mercy (Misericórdias), Local Authorities, Local Drives Health and charities), for a period of three years to ensure its sustainability and further integration with the National Network for Continuing Care.

MENTAL HEALTH

In the past decade, mental health has become a key priority for the Portuguese health sector, and a National Mental Health Plan 2007-2016 was established. The research underpinning the plan showed that mental health services suffer serious deficiencies in terms of accessibility, equity and quality of care.[21] Only a small proportion of those with mental health problems have access to public specialised mental health services. The majority of resources continue to be concentrated in Lisbon, Oporto and Coimbra, and professional health workers are concentrated in hospitals in urban centres. Hospitalisation continues to consume the majority of resources (83%), while all scientific evidence shows that interventions in the community, closer to people, are much more effective and preferred by patients and their families.[22, 23]

The Commission's view here is simply that the existing plans need to be rolled out in order to provide a higher quality and more community based service in the future.

A recent report published jointly by the Calouste Gulbenkian Foundation and the WHO on the social determinants of health stresses the importance of tackling mental health across the whole life course but also highlights the need to give every child the best start in life – for their benefit but also for the benefit of society at large.[24] This is an important theme that will be returned to in the final chapter of this report.

ACUTE AND SPECIALIST SERVICES

Whilst community and home based services need to expand and create a diversity of provision, acute and specialist services need to become more concentrated and, in many ways, more standardised around set processes and protocols.

Acute and specialist services are generally very well regarded in Portugal. However, as described in the last chapter, there are considerable variations in practice and quality. Many stakeholders told the Commission of the necessity of making changes to concentrate specialist services and create specialist networks that link facilities across cities or large parts of the country in order to improve standards. This would also release funds and staff to develop community services.

This has proved particularly controversial and divisive in the past. The clinicians and patients who advocated this were motivated by the need to improve quality and safety. They stressed the need to concentrate expertise and pointed to the risks involved in specialist procedures being undertaken in relatively ill-equipped facilities without the full range of expertise and back-up services, thereby compromising both quality and safety. The Commission also heard of examples where these changes were already happening with hospitals cooperating to provide specialist services across a city or wider area.

These changes, which will mean service, and in some cases, hospital closures are almost always opposed by the public – who see them simply as "cuts" and as reductions in service – and by some health workers whose interests are affected. The Commission notes that the Ministry has recently published a hospitals plan for the country which consists of describing what role each hospital would play in the future. It believes, however, that it is vital that the distribution of specialist services are reviewed in terms of quality and safety and that specialist network of care are created which link clinicians in the remotest areas with academic and specialist centres and engage patients. The Commission's earlier recommendations about quality, the use of knowledge and the need for greater openness and transparency of information will all help bring this about.

The example of ParkinsonNet described here is in many ways a model for future specialist service provision. It is based around technology enabled networks that engage patients as well as practitioners, is multidisciplinary and firmly evidence-based. It is a model that could be replicated with other specialties. The second example describes cancer networks in the UK which, whilst not engaging patients as well as ParkinsonNet, shows how specialists and generalists from hospital and primary care can work together through shared protocols and processes to provide evidence based care for their patients.

The central point here is that these networks can reach every part of the country with the highest quality care.

ParkinsonNet in the Netherlands

ParkinsonNet has developed regional care communities of healthcare professionals who specialise in Parkinson's disease. The participating professionals are selected and (continuously) trained in use of evidence-based guidelines and supported in their communication and collaboration. In addition, ParkinsonNet carries out research and develops evidence-based clinical practice guidelines.

People with Parkinson's disease are able to find these specialised health professional through a search engine on the ParkinsonNet website. They are also able to see all the evidence and guidelines and access information and data when they want to. The network is founded on the basis of shared care and shared decision-making between professionals and citizens.

Through the re-organisation of care, ParkinsonNet increases the expertise of health care professionals, quality of care and patient health, as well as reduces societal costs. In 2010 national coverage within the Netherlands was achieved by 66 unique, multidisciplinary networks.

Cancer networks in England

Cancer Networks are an organisational model for cancer services, established in the UK in 2000 under the Cancer Plan. These care networks reach from primary care to cancer units, treating the more common cancers and assessing and diagnosing rarer cancers, to cancer centres, treating the rarest cancers and providing highly specialised treatment such as radiotherapy and bone marrow transplantation. They bring together health service commissioners (health authorities, primary care groups and trusts) and providers (primary and community care and hospitals), the voluntary sector, and local authorities. Each network will typically serve a population of around one to two million people.[25]

Through cancer networks, services can be planned across the care pathway for cancer patients with resources targeted where they are most needed to serve the cancer needs of their local population – which may not be in the local hospital. Seamless care is promoted and alliances can develop to help reduce the risk of cancer, through action on smoking and diet.

Cancer networks have already proved very effective in many areas – notably the nine networks involved in the Cancer Services Collaborative. More recently, in January 2014, NHS leaders launched a new five year plan to transform cancer services in the capital to meet the soaring numbers of Londoners surviving cancer.[26]

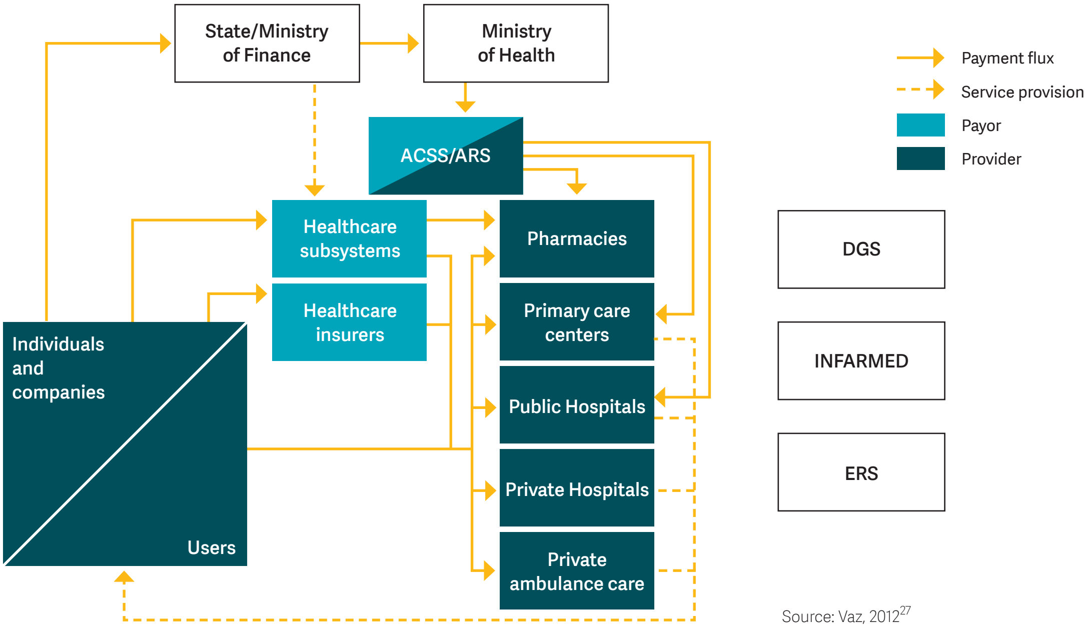
ORGANISATION

This major re-shaping of services envisaged here will change the nature of the health care infrastructure throughout the country. Over time there will be fewer and more specialised hospitals with far more services provided locally and electronically. This will be a major transition programme which will take a number of years to complete. It also needs to be planned, managed and monitored appropriately.

This planning, management and monitoring will have two parts. Firstly, the Ministry of Health has overall leadership for the SNS and responsibility for the development and maintenance of the whole health system. It has management, planning and monitoring processes through which it can deliver the necessary changes. Secondly, the Commission has proposed the creation of the National Health Council in Chapter 1 as a whole of society alliance which could own and refine the vision for the future, take an overview of the system and advise on policy in line with this vision. It should be representative of citizens and all sectors of society and independent of politics and report to Parliament, the Cabinet through the Minister of Health and the public.

The Portuguese SNS which, like any other national health system, has grown up and been amended and re-amended over 40 years, is both complex and particular to the country. Figure 3 provides a simplified overview of the system which illustrates the key features.

Figure 3 · **The current structure of the Portuguese health care system**



Source: Vaz, 2012[27]

The Ministry of Health provides the overall leadership and policy for the SNS and regulates the whole health sector. It undertakes many planning, regulatory and management functions either directly through its own officers or indirectly through public institutes or state owned companies. Its direct administration includes the Directorate General of Health with responsibility for all public health programmes, quality, epidemiological surveillance, health statistics and studies; the General Inspectorate of Health-related Activities providing audit services; the General Secretariat offering coordination and technical support; and the Authority for Blood and Transplantation.

The 1979 law establishing the SNS stipulated that there should be centralised control but decentralised management and the direct management of the service is undertaken through 2 public institutions: the Central Administration of the Health System (*Administração Central do Sistema de Saúde*) and the Regional Health Administrations (*Administrações Regionais de Saúde*), which are shown in Figure 3 as ACSS and ARS.

The five regional health administrations – North, Centre, Lisbon and Vale do Tejo, Alentejo and the Algarve – each have a board accountable to the Minister of Health, and manage the SNS regionally. They undertake the strategic management of population health, the supervision and control of hospitals, and have direct management responsibility for primary care and SNS primary care centres.

The ACSS is in charge of the management of financial and human resources, facilities and equipment, systems and information technology. It is also responsible for the definition of policy, regulation and planning of health and for working with the ARS on health service contracting.

The five regional health administrations – North, Centre, Lisbon and Vale do Tejo, Alentejo and the Algarve – each have a board accountable to the Minister of Health, and manage the SNS regionally. They undertake the strategic management of population health, the supervision and control of hospitals, and have direct management responsibility for primary care and SNS primary care centres. They are responsible for the regional implementation of national health policy objectives and coordinating all levels of healthcare, including the establishment of agreements and protocols with private bodies and liaison with Government bodies. The autonomous regions of Azores and Madeira have their own regional health systems.

Services are provided, as shown in Figure 3, by a mixture of SNS organisations and private for-profit and not-for-profit organisations. The various central bodies – represented on the right of Figure 3 by the Directorate General of Health (*Direcção-Geral da Saúde*, DGS) the Pharmacy Regulator INFARMED and the Health Regulatory Authority (*Entidade Reguladora da Saúde*, ERS) – also play a variety of regulatory and service roles in relation to the service providers.

Figure 3 shows in the bottom left corner how funding comes into the system from individuals and companies in the form of tax, insurance premiums and moderating costs. The Ministry of Finance uses the 70%+ of tax funding to fund the Ministry of Health, while the sub-systems are subsidised directly from the Government budget. The Ministry of Health in turn funds the central and regional administrations, which alongside the sub-systems, fund the service providers.

With growing competition in healthcare and greater devolution in the SNS, the ERS was created in 2003 outside the Ministry of Health, and is responsible for competition policy and the economic regulation of the healthcare sector. It was reformed in 2009 and now aims to ensure that providers meet their requirements for service delivery, that access to healthcare and patients' rights are guaranteed and to ensure competition between providers.

The Ministry of Health has an obligation under the Portuguese Constitution to formulate a plan for the SNS and, for the first time developed a national health strategy and healthcare policy with quantified objectives and targets in 1998. More recently, SNS priorities were brought together in 2004 in a National Health Plan (2004–2010) and a High Commissioner for Health was appointed in 2005 to ensure that it was implemented.[28] This was followed up by the current Plan for 2011 to 2016; although there is no longer a High Commissioner in post to ensure implementation. The priorities were identified by the Ministry of Health in 2012 as being nutrition, cancer, cardiovascular disease, diabetes, respiratory disease, mental health, tobacco control and HIV/AIDS. Subsequently, health care associated infection and anti-microbial resistance were added as a jointly managed ninth priority.

REDESIGN OF THE HEALTH SYSTEM TO MEET THE NEEDS OF THE FUTURE

The SNS is a complex system which has grown up over time with new organisational arrangements added on top of existing ones. The result is that it is difficult both to make decisions and to be clear who is ultimately accountable for what. The existence of three bodies with some, apparently over-lapping, responsibility for overseeing quality in the system was noted in Chapter 4. The Commission heard many complaints from stakeholders about administrative processes, lack of decision-making and confusion over responsibilities and roles. The Commission also found evidence to agree with other commentators who said that there is: “*no shortage of policy in Portugal … only of implementation*”.[7]

The Commission is not proposing a wholesale change in the system in part because such a change would be very disruptive, time consuming and costly; but also because much of the system works well. There are however, some strategic changes that are needed to improve its performance. In particular the Commission believes that it is now essential to review and clarify responsibilities and accountabilities and simplify the whole system. This is particularly timely in view of the changes already underway in the system and those proposed in this report. This review should aim to create a system fit for the challenges of the future and drawing on all the design principles which were listed in Chapter 1 and are reproduced in Figure 4 below.

Figure 4 · **Design principles for a high quality and sustainable health and health care system in the 21st century**

A HIGH QUALITY AND SUSTAINABLE HEALTH AND HEALTH CARE SYSTEM IN THE 21ST CENTURY NEEDS TO BE:

- **Broadly based** – built on a shared vision that addresses all the determinants of health
- **Values driven** – ensuring that the whole population is provided for equitably
- **Inclusive** – involving all sectors of society
- **Accountable** – with clarity about responsibilities, authority and reporting to the public
- **Open and transparent** – with citizens owning their own information and able to access information on the quality and costs of services
- **Person-centred** – where care is compassionate and safe, integrated and personalised for each individual and with patients fully involved in decision-making
- **Local and accessible** – with services, wherever possible, provided in the home or local community and decision-making devolved as locally as possible
- **Partnership and team-based** – ensuring cooperation and knowledge sharing amongst clinicians and with citizens and partners
- **Evidence-based** – with evidence available and used throughout the system
- **Focussed on continuously improving quality** – and on implementation and learning
- **Resourceful and economical** – making the best use of available resources and avoiding waste

All of these are important; however, the Commission would particularly draw attention here to the importance of accountability, openness and transparency and to the need for local and accessible decision-making involving citizens and patients. This review should clarify accountabilities and introduce better arrangements for holding individuals and organisations to account. This should be accompanied by much greater transparency about data, processes and performance. The Commission noted that, despite changes in recent years, there was still a feeling amongst some people that too much information was kept secret and too many appointments were politically influenced. Whatever the truth of such feelings, it is imperative to deal with them by opening up data and processes to wider scrutiny.

This review should lead to a reduction in the number of national bodies with a role in the system and cut overhead costs. The Commission has not attempted to quantify possible savings in the number of bodies or costs but would be very surprised, based on experience of similar reviews in other countries, if savings in the numbers of organisations and costs were not at least 25% and probably considerably higher. This funding could be re-invested in the proposed SNS Evidence and the agency for quality and implementation and in strengthening public health.

The review should be undertaken in line with the design principles in Figure 4 and with three principle aims in mind:

1. To promote local accountability by devolving increased authority to SNS organisations locally and to reduce the burden of unnecessary or duplicated regulation and supervision

2. To transfer funding from supervisory and regulatory function to those supporting implementation and delivery

3. To improve accountability and decision-making and thereby improve the functioning and efficiency of the whole system

PARTNERSHIPS IN PLANNING AND SERVICE PROVISION

Earlier chapters have dealt with the importance of partnership in planning and delivering services – in line with the design principles described in Figure 4 above. Much of the discussion has been about developing partnerships with other parts of government, municipalities, patients' organisations and charities. These are generally non-contentious issues, however there is considerable disagreement about the involvement of private for-profit organisations in the SNS whether through the creation of new facilities or through providing services on a contracted basis.

Many of the arguments about this revolve around ideology and politics – with some people seeing the private sector as the potential saviour of the SNS and others seeing it as the potential destroyer. The Commission's view is practical and pragmatic. Based on experience and evidence from elsewhere, it has concluded that private organisations can play a significant role in bringing new skills, resources and enterprise to the SNS. However, this needs to be done within a clear national framework and as part of an integrated system which minimises risks and maximises these benefits.

Competition, between SNS organisations or with the private sector, is discussed in Chapter 7. There are two key sets of questions here. The first are about values and objectives and about ensuring that actions are taken for the public and patient good and not simply for private gain. The second are operational and are about how to ensure that engaging private organisations does not lead to "supply induced demand" – where capacity is used simply because it exists or is marketed – and about how to ensure the services don't fragment but can be integrated successfully for each individual.

The commission recommends that both these sets of questions are dealt with by the creation of a Public/Private Concordat which would set out the framework for the engagement of private sector organisations. This would need to cover all the points contained in Figure 4 – embracing, for example, shared values and transparency – and would place the same operational requirements on private sector organisations as are placed on SNS ones.

This accords with the advice given by the WHO in 2010 when it recommended that Portugal should: "*Clarify the role of the private sector through a coherent policy framework: regulate and ensure compliance with requirements for public reporting, standards of quality and safety, rules for dual employment, and pricing and payment mechanisms.*"[29]

CONCLUSIONS AND RECOMMENDATIONS

The need for the health system of the future to be person-centred and able to provide integrated care for each individual brings with it enormous changes. These provide the opportunity for enormous creativity in the development of new service models and for the redesign of the health system to meet the needs of the 21st century. As this chapter has shown, Portugal has many of the key features in place which will allow it to improve its service and systems. There are, however, some immediate actions needed, to accelerate and consolidate the necessary changes.

This chapter has drawn heavily on Working Group 1's deliberations and on input from many different stakeholders. Following discussion with the Group and further deliberation, the Commission has decided to make three recommendations here.

RECOMMENDATIONS

14. **NEW MODELS OF CARE.** Policy makers, planners and providers need to work together to create services which provide integrated care for all individuals with particular emphasis on: chronic disease management; the development of more services in the home and local community; and the creation of specialist networks – based in reference centres but reaching all parts of the country through technology and shared protocols.

15. **ACCOUNTABILITY AND OVERHEADS.** Accountabilities need to be clarified across the whole system and there needs to be a review of the number and roles of the many national bodies associated with health and care, reducing their numbers and costs by at least 25% and releasing funds for investment elsewhere.

16. **PUBLIC PRIVATE CONCORDAT.** A public/private concordat needs to be developed as a framework for the engagement of private providers in the SNS which safeguards the public interest whilst bringing potential new resource and innovation to the health system.

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New roles and strengthened leadership

6

Health professionals are well suited to be agents of change and improvement, but leadership is needed in all sectors and in communities and leaders need to work together. Professionals need to take on new roles – with their education adapted accordingly – whilst patients and community organisations need support to take on greater leadership roles.

LEADERSHIP AT ALL LEVELS

Health professionals have a particular role to help shape services, advise on policy, guide their colleagues and lead by example. However, leadership in health care very often needs to be shared between people who can bring together different experiences and expertise and engage different constituencies. Successful services and organisations are almost always characterised by good teamwork and by the different leaders – medical, nursing and managerial – sharing a vision, acting together and each making sure they and their people play their part. This sort of collective leadership or leadership coalition can be extremely powerful.

Earlier chapters have dealt with the importance of creating cross-sectoral leadership through, for example, the proposals for the creation of the National Health Council and for involving citizens on the boards of SNS organisations. More widely, leadership is needed at every level: in the ward and operating theatre as well as in Government; in municipalities and schools as well as in health centres; by citizens and volunteers as well as by the most highly trained professionals. Almost everyone has some role in leadership and almost all leadership in the complex world of health needs to be exercised jointly with others.

This chapter addresses specifically the health workforce and looks at the changes that are needed in the future in a world where citizens and patients play much more powerful roles and at how these changes can be brought about. It looks in turn at:

- Health professionals – the agents of change
- Professional education
- The development of new and extended roles

TODAY'S REALITY

The health system is built on the skills of the professionals and other health and care workers who deliver care and treatment, undertake teaching and research, and support citizens and patients with their needs. The greatest benefit in health care and the largest cost comes from staffing which, in Portugal, as elsewhere, amounts to more than 60% of total SNS costs. The vision for the future presented here, with the new emphasis on action by citizens and society, brings both unsettling change and exciting opportunity. On the one hand, long established practices will need to change and new relationships will need to be created. On the other, closer partnerships with patients and the potential of new technologies will create new possibilities.

All these proposed changes are coming at a time when many health workers are feeling under enormous pressure in terms of maintaining services. Many are also affected personally, with their salaries reduced and cuts in future pensions and benefits. The Commission also heard that younger professionals are very concerned about employment prospects for the future. Nursing and medical students are facing job shortages after graduation due to increases in university intake. Courses are oversubscribed, with as many as 20 students observing one professor on ward rounds. The concentration of training and education in towns and cities means that trainee health professionals prefer to study and practice in urban centres, exacerbating rural shortages.

Given these pressures and concerns, it is a tribute to the dedication of Portuguese health professionals that the Commission found so much enthusiasm and determination to make improvements within the system. It can be hard to be enthusiastic about the future when you are uncertain about how you personally will fit into it, if at all. There is a challenge for leaders at all levels within the system to:

- be open and honest with their colleagues about the situation, sharing what they know and being accountable for their decisions
- provide as much space as possible for people to "own" and shape the changes that are affecting them

The Commission's recommendations on transparency, governance and accountability can help with the first of these challenges; whilst the development and use of quality improvement methods – which engage front line staff in making improvements – can undoubtedly assist with the second. Perhaps, most importantly, of all, however, is the need to identify and support health professional leaders who can provide the vision and inspiration to motivate the whole workforce.

"Nowadays health professionals are expected to control illnesses and to be pro-active relatively to the prevention of acute episodes and possible complications."

The changes that young health workers can anticipate over the next 25 years will be enormous in terms of their relationships with patients, the skills they will need to develop and the way in which they will have to practice. The Commission was told about the need for changes in education and staff roles by almost all stakeholders, including the professional bodies and by all four of its Working Groups. Working Group 2 described this from the patient's perspective and, as others did, stressed the importance of teamwork:

> *"The main role of a health professional is usually associated with the analysis of the patient's symptoms, diagnosis and therapeutic prescription; which is, in sum, insufficient. Nowadays health professionals are expected to control illnesses and to be pro-active relatively to the prevention of acute episodes and possible complications. Around 80% of persons that resort to primary care services suffer from chronic diseases.*
>
> *Health professionals are used to speaking with patients about their illnesses; however, they do not teach them to manage their new condition within their day-to-day lives. In order to teach and monitor their patients, health professionals need to better understand patients and the relation they have with health and illnesses. More than health technicians, they need to be pedagogues, psychologists, sociologists and anthropologists. Finally, working teams must be multidisciplinary, which will enrich, complete and sustain knowledge concerning citizens and their health conditions."* [1]

The other Working Groups also stressed the need for change and for health professionals to be better educated in public health and quality improvement and well prepared for a time when there will be far more use of information and communication technologies.

These challenges are common to the other countries of Western Europe where health systems are having to respond to changed needs and a changed environment. The OECD report on Portugal – in a statement that could have applied equally to many any other countries – advised that Portugal should:

> *"Secure the appropriate supply and skill mix of health professionals to respond to the current and future needs of the population, particularly people with chronic conditions and long-term care needs, by training more nurses and care personnel and promoting task-sharing among different professionals."*[2]

THE HEALTH WORKFORCE

The Portuguese health workforce has some particular features. Table 1 shows changes in the numbers of key groups of staff within the SNS over the last 2 decades. A number of points stand out within this picture of across the board increases:

- There has been a very large increase in nursing staff from a very low base. Portugal has proportionately more doctors and dentists than the European (EU27) average but still has fewer nurses and a low ratio of nurses to doctors
- Portugal is self-sufficient in medical staff, with a small number of foreign doctors – 1,903 or around 5% in 2007 – and sufficient capacity in its medical and nursing schools to be a net exporter
- It is estimated that about half SNS doctors also work in the private sector – as do a significant number of nurses – whilst many private doctors also work under contract in the SNS
- Many dentists and pharmacists work exclusively in the private sector and the trend has been increasing in recent years

Table 1 · **Healthcare personnel, 1990–2012 (selected years)**[3]

	1990	1995	2000	2005	2010	2011	2012
Doctors	28 016	29 353	32 498	36 183	41 431	42 796	43 863
Nurses	28 154	34 225	-	48 155	62 433	64 478	65 404
Dentists	667	1 411	3 321	5 056	6 972	7 366	7 533

Almost all the people working within the SNS are civil servants: although there are some differences in terms and conditions between, for example, hospital doctors and GPs. Whereas over the last 10 years hospital doctors are increasingly often on short-term contracts and have part of their pay determined by their hospital, GPs are usually on permanent contracts which are nationally determined. Some attempts have been made to introduce more performance-related contracts, but none have become widespread.

Although there are no systematic international studies available, anecdotes suggest that there has been relatively little extension of nurses' roles compared to some other Western European countries; in part perhaps due to the relative proportions of nurses in the system. The Commission noted that there was legal provision to appoint a Chief Nursing Officer for the country but that this post has never been appointed to. Similarly, there seems to have been relatively little in the way of redesigning jobs or introducing new cadres, such as physicians assistants, compared to some other European countries.

Practising physicians must belong to the *Ordem dos Médicos* which accredits and grants licences to practice; accredits and certifies specialist training; and applies the disciplinary code. There are also equivalent bodies for nurses, pharmacists, dentists and psychologists, which represent their professions and, like the doctors' ones, are regularly consulted by the Ministry.

AGENTS OF CHANGE

There have been many recent reports internationally on the changing and future role of doctors and other health professionals. The Lancet Commission on *Health Professionals for a New Century* sets out the view that health professionals need to become "*agents of change*" in the future. [4] It sets this in an historical context noting that the first wave of medical education following the Flexner Report of 1910 provided medicine with a scientific basis and that the second wave of "problem based learning" brought a clearer orientation to understanding disease in the context of a patient. Now it argued medical education needed not only to be scientific and "problem based", but also to be undertaken with an understanding of systems and of how medicine and health interact with the wider world.

Doctors, it argued, need to be equipped not just as a scientific expert or as a professional equipped to look after individual patients. Doctors in future also needed leadership attributes and the ability to be transformational leaders or "*agents of change*" who would be able to improve health through understanding how systems work and leading teams to deliver improvement.

The Lancet Commission's vision, which was global and went beyond medicine to include all health professionals in clinical and non-clinical roles, was:

"*All health professionals in all countries should be educated to mobilise knowledge and to engage in critical reasoning and ethical conduct so that they are competent to participate in patient and population-centred health systems as members of locally responsive and globally connected teams.*"[4]

This is not just a vision of what leading professionals may do in the future but a reality for some people today. The Commission heard from three transformational medical leaders at a conference held in February 2014 to review leading edge practice from other countries in 2013. Each of them shared certain characteristics which included: a focus on the individual person or patient; a passion to improve their service; being prepared to take responsibility for changing it;

planning change on the basis of evidence even where this went in the face of current practice; finding creative and new solutions that crossed traditional boundaries; managing the impacts of the changes they were making on other people and other parts of the system. Crucially, they understood or learned how to use and adapt the wider system to help them achieve their aims. These characteristics are listed in Figure 1.

Two of their accounts are included as examples in this report: the Scottish Early Years Collaborative in Chapter 2 and ParkinsonNet in Chapter 5.

Figure 1 • **Characteristics of transformative leaders or *agents of change***

CHARACTERISTICS OF TRANSFORMATIVE LEADERS OR AGENTS OF CHANGE

- Person-centred
- Passion for improvement
- Willingness to take responsibility and lead
- Use of evidence
- Creative thinking that crosses boundaries
- Managing impacts elsewhere on people and practices
- Using the system to achieve success

LEADERSHIP AND MANAGEMENT

There are similarly inspiring and successful leaders in Portugal. The important question here is how to support and develop even more for the future. Whilst Portugal has a tradition of individual leaders and champions who have pioneered new ideas, developed services and improved life immensely for their fellow citizens, leadership is not systematically developed and supported at scale in Portugal.

More leadership programmes need to be developed within the health system and will need to take place alongside leadership development in the wider public realm. Educational professionals, citizens and leaders of municipalities, for example, will all contribute to improvements in health and well-being. All of them, including health professionals, can contribute to improvements in society more widely.

There is also a need for greater management skills across the system. Whilst top managers may have the skills and experience necessary for their roles, it is generally middle and junior managers who are involved in the day to day decisions which affect what actually happens to and for patients. The approach to quality improvement described in Chapter 4 will require the involvement of empowered and able middle and junior managers as well as clinical staff. Moreover, there is also a need for more clinicians to acquire management skills so that they can take a stronger role in the organisation of their services.

The Commission is not making a particular recommendation in this area but does think that more needs to be done to build on existing leadership and management programmes to strengthen capabilities in this area both for its own sake and to allow for the successful implementation of the changes proposed here.

PROFESSIONAL EDUCATION

Working Group 2 on Staffing the Service produced three reports for the Commission on professional education, skill mix change and workforce planning all of which contained powerful and radical proposals. Their core recommendations are reproduced below.

In all three cases, their thinking has been influenced both by experience in Portugal and by developments elsewhere. Their analysis of professional education has drawn on the Lancet report mentioned above amongst other sources. The Commission found that it also echoed some of the concerns medical students had told it about. In particular there was concern that the undergraduate medical curriculum did not address topics they would need in later life. These curricula, which are established by each School and published by the Ministry of Education appear not to be sufficiently linked into current policies and developments.

Working Group 3 set out five major proposals on reforming professional education: [5]

1. Promote a new joint approach between the Ministry of Education and the Ministry of Heath on planning undergraduate education level especially on the *numerous clausus* which is established unilaterally by the university. This would need to address the existing problems that there are currently too many graduates, which is likely to lead to high unemployment levels amongst clinical staff, and undergraduate education is currently very high cost. The Group recognised that this approach would be unpopular with universities which would lose income and with potential future students.

2. Reform the classic education model based on theoretical education for core competencies provided in universities followed by clinical training, mostly in hospitals. This reform would address the facts that more care needs to be provided outside hospitals; primary care is now recognized as the basis of SNS sustainability; and there is currently a lack of capacity to attract and maintain SNS professionals in the primary care setting. The Group recognised the scale of change needed here and noted that health centres and GP practices would need to re-organise themselves to support community-based training and develop educational initiatives that address primary care practice.

3. Promote inter-professional education as a tool to break down current professional silos, while enhancing collaborative and non-hierarchical relationships in effective teams. The Group argues that health professionals must work collaboratively and in fully functional teams if the nation's health care system is to better meet the needs of patients. Collaboration and teamwork can best be achieved if it starts early, with students from different professions engaging in interactive learning with each other. Health care delivered in teams is more efficient and more effective. The Group recognised the scale and complexity of the changes involved both educationally and administratively and proposed starting at the pre graduate level designing a curriculum with common contents for the students of medicine, nurses, pharmacists, psychologists and other technicians.

4. Re-certification and re-validation should be required because there is an increasing mismatch of professional competencies to health needs, partly due to fragmented curricula, as well as static continuing education. The Group proposes that: there should be innovative approaches in continuing education in order to enhance its effectiveness, education should be embedded in the daily clinical practice, employing self-directed learning as a principal method; self and peer assessment of competencies should be promoted; and that the process should bring together physicians, nurses and other health professionals to support teamwork.

5. Launch transformative learning so as to develop leadership attributes and produce the *enlightened change agents* described in the Lancet report. The Group proposes that this should include: designing postgraduate education on a basis of critical reasoning promoting the capacity to search, analyse, assess, and synthesize information for decision-making; creat-

ing new professional credentials with competencies for effective teamwork in health systems; adapting the educational models to the needs and resources to address local priorities; creating institutional incentives; and including teamwork and leadership training as a core content in each portfolio.

These proposals are far reaching and will take time to implement. They will, however, play a very important role in creating the workforce needed for the future. Changes in education need to be accompanied by changes in the roles that people will play in the future.

HEALTH WORKER ROLES AND SKILL MIX CHANGE

The roles undertaken by different health workers are changing throughout the world as citizens and communities take on bigger roles and as science and technology advance. Under the right circumstances and with the right training, some things that were once only done by professionals can now be safely done by patients and roles only undertaken by doctors can be safely done by others. There is increasing evidence of where and how to do this effectively.[6] Working Group 3 set out a number of proposals in this area. [5, 7]

> Under the right circumstances and with the right training, some things that were once only done by professionals can now be safely done by patients.

It advocated:

1. The launch of a task force on assessing the skill mix of the Portuguese human resources for health.
   It noted that international evidence suggests that, under specific circumstances and with the appropriate training, task shifting can improve access and patient satisfaction without quality or safety loss. It recognised that there were compelling reasons to do this including the changes in disease patterns, the role that technology could play in supporting health workers and the demographic and economic pressures. It noted that there would be resistance to change from some stakeholders but believed that these could be overcome – as they had been elsewhere – by engaging clinicians as leaders and taking a measured and evidence based approach.

2. The immediate introduction of two new roles:

    - A family nurse. This role was in fact approved for implementation by the Government in a decree on 19th June 2014. Literature reviews indicate the great potential of such multi-skilled generalist nurses in meeting the requirements of the changes in health systems across Europe. The Group noted that: the formal role already exists in law but has not been introduced; there is a collaborative atmosphere of primary care settings in the Family Health Units; there is a perceived urgent need to reinforce primary care delivery; and there is a shortage of general practitioners, stretched with basic tasks and treatments.

    - A broader community pharmacist role. The Group noted that pharmacists can play an important role in medication adherence and the prevention and detection of Drug-Related Problems with positive clinical, economic and humanistic outcomes. Community pharmacists are ideally placed to collaborate in health promotion and disease prevention activities. It also noted that there was an increased awareness of the costs of medicines and of patients not taking them as prescribed; a new emphasis on patient empowerment; and that the community pharmacies proximity to the citizen, allows for opportunistic interventions.

The Working Group also advocated a new approach to workforce planning.[5] It stressed the importance of forecasting and planning aimed to match the supply and demand for different categories of health workers, both in the short and longer-term. Workforce planning in the health sector is particularly important, given the time and cost involved in training health professionals. It argued that health workforce planning is needed not only to guide policy decisions on entry into health professional's education programmes, but also to assess the impact of possible re-organisations in health service delivery to better respond to changing health care.

The key challenge it saw here was to align the national priorities of the health with the education and research sector. The current EU policy on mobility of labour gives a further impetus to collect accurate data on the health workforce, including the migratory flows. As the Working Group said, there is little benefit in educating adequate physicians, pharmacists, nurses and others for them just to migrate to other countries because the labour market cannot integrate them, or because working conditions are not attractive enough.

CONCLUSIONS AND RECOMMENDATIONS

The Commission recognises the enormous pressures for change that are affecting the health workforce and notes, in particular, the importance of good leadership from health professionals in leading improvement.

This chapter has, as has been noted, drawn heavily on Working Group 3's deliberations and on input from many different stakeholders. Following discussion with the Group and further deliberation, the Commission has decided to make two recommendations both of which it believes will have long-term strategic impacts.

RECOMMENDATIONS

17. **PROFESSIONAL EDUCATION.** The Ministries of Health and Education should set up an inclusive process to review professional education in the light of current and future developments in health and ensure that it embraces the new needs for partnership with patients, quality improvement and public health.
18. **NURSING.** The status of nurses within Portugal should continue to be raised by appointing a Chief Nursing Officer, extending their roles and, as funding allows, increase their numbers. Following the introduction of the new family nurse role, consideration should be given to extending the role of nurses and other professionals in other areas.

References

[1] Working Group 2, Gulbenkian Commission: Future for Health (2013) *Working Group 2: Citizens and Patients* (2nd report).

[2] Conceição C, JS Ribeiro, J Pereira, G Dussault (2011) *Portugal: Mobility of Health Professionals*. Associação para o Desenvolvimento da Medicina Tropical. Instituto de Higiene e Medicina Tropical, Universidade Nova de Lisboa.

[3] Pordata (2014) pordata.pt

[4] Frenk J and Chen L (2010) Lancet Commission: Health professionals for a new century – transforming education to strengthen health systems in an interdependent world. *Lancet*, 376 (9756): 1923-1958.

[5] Working Group 3, Gulbenkian Commission: Future for Health (2013) *Working Group 3: Staffing the Service* (2nd report).

[6] WHO (2008) *Task shifting. Global recommendations and guidelines*. who.int/healthsystems/TTR-TaskShifting.pdf

[7] All Party Parliamentary Group on Global Health (2013) *All the Talents – how new roles and better teamwork can release potential and improve health services.* July 2013.

Financial sustainability

7

The vast majority of costs in the health system come from caring for people with long-term chronic conditions. Financial sustainability will only be achieved though reducing the incidence of these diseases and the associated morbidity, developing new models of care for them and making sure evidence is applied systematically everywhere and waste reduced to a minimum. New financial mechanisms and outcome-based incentives can help if managed well; but the financial salvation of the system will depend on political willingness to introduce health into all policies, effective health promotion and concerted action by citizens, wider society and health professionals.

HEALTH, CITIZENS AND SOCIETY

Throughout this report the Commissioners have recognised that in order to improve health the emphasis must be placed on health, citizens and wider society rather than on the health system itself. It has approached finances in the same way. It has also been very careful to ensure that it is taking a long-term view of financing and sustainability – looking up to 25 years ahead – and not seeking short term fixes for today's financial problems.

A few features of health in Portugal stand out:

- There are very high levels of diabetes and other long-term chronic conditions
- Older people in Portugal have higher incidence and longer periods of morbidity – ill health and disability – than in other European countries
- There is a great deal of variation in services and outcomes

All of these affect not only the quality of life of individuals but they also increase costs, with the biggest burden on the health system coming from people with multiple long-term conditions. Moreover, home and community services need to be developed alongside health promotion and health literacy programmes in order to tackle these major issues.

It therefore makes sense in financial as well as health terms to target improvements in services and costs on three areas: reducing the morbidity associated with long-term chronic conditions; applying evidence and knowledge systematically to improve quality and reduce waste; and changing the infrastructure of service delivery.

This approach needs to be supported by improving accountability and efficiency and by introducing and using the appropriate financial levers to bring about improvements. In common with other countries, Portugal has begun to develop and experiment with many different measures for managing rising expenditures including: changing incentives, introducing competition, improving commissioning of services, and increasing income from user fees, taxes and other sources. International experience shows that these can provide some benefits if implemented well and in the right circumstances; but can be very damaging if applied badly and in the wrong situations. Whilst there is absolutely no evidence globally that they can provide the scale of impact that is needed to make a health system sustainable, adequate and appropriate financial mechanisms are necessary to support the system.

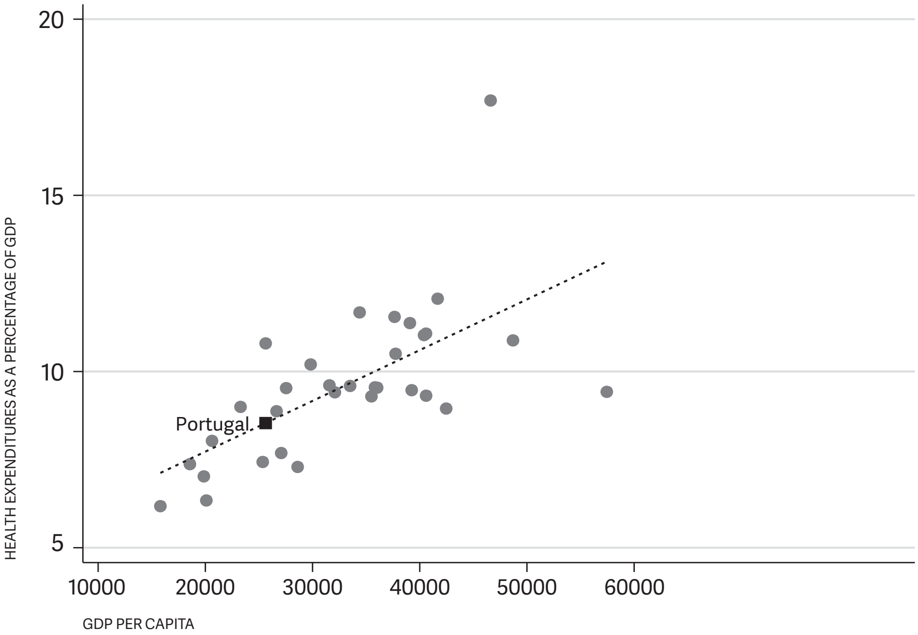
The implication of this argument is that the financial salvation of the health system will not come from the design of sophisticated incentives and financial mechanisms at the centre. The financial sustainability of the system will depend mainly on political willingness to introduce health into all policies and on action by citizens and society as well as by the health professionals and managers who apply evidence and new service models to manage patients better. The government has the responsibility to provide the environment in which they can do so.

This chapter addresses these issues in more detail, starting by looking at how Portugal compares internationally.

INTERNATIONAL COMPARISONS

Portugal spends very much the same on health services as other countries in Western Europe as a percentage of GDP and in per capita terms (at purchasing power parity). Figure 1 shows that Portugal is precisely on the trend line when total expenditure on health as a percentage of GDP is compared with GDP per capita. Other analyses, for example of Portugal's total health expenditure as a percentage of GDP, equally show that Portugal is an average spender.

Figure 1 · **Portugal's total health expenditures as a percentage of GDP related to GDP per capita compared with other OECD countries in 2011**



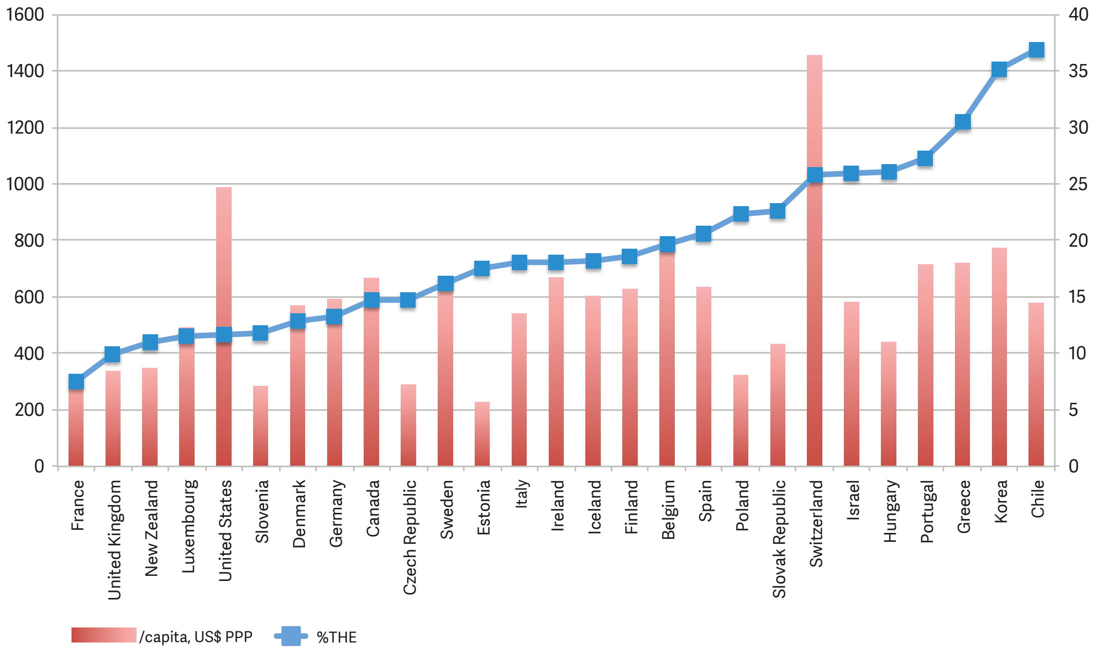
Source: OECD Health Data 2013

Comparison of expenditure, of course, only provides part of the picture and needs to be complemented with data on what has been achieved with the money – in other words, in outcomes for the population's health and quality of life. Looking at broad aggregates, like mortality rates, Portugal is again within a normal range. However, as noted earlier, Portugal has significantly higher levels of morbidity in some areas, particularly amongst older people.

The other important differences to note are that Portugal has a lower level of state expenditure than most countries and a correspondingly higher level of private expenditure. The big difference here being the very high level of out-of-pocket expenditure in Portugal, with only a small amount of private insurance. It also spends less on long-term care.

Turning first to out-of-pocket expenditure, private spending in the Portuguese health care system is among the highest in the OECD countries both as percentage of total health expenditure and in per capita US$ (at purchasing power parity). Figure 2 shows the total expenditure that the population pays "out-of-pocket" rather than through their taxes or insurance contributions. The figure shows that Portuguese people pay about $700 a year in out-of-pocket payments – which is more in cash terms than the French (on $250) , British ($350) and Germans ($500). The figure also shows that they pay out-of-pocket – rather than through taxes or insurance premiums – about double what the Americans pay as a proportion of total health care expenditure.

Figure 2 · **Out-of-pocket payments for selected OECD countries in 2013**



International comparison of out-of-pocket payments, with data extracted from OECD data base 2013 (extraction date: 03May2014)

This private spending is dominated by the large co-payments associated with the SNS coverage of pharmaceutical products and laboratory tests and exams. Most public controversy and discussion about co-payments, however, is currently about the user charges paid for SNS services rather than about these pharmaceutical costs. These user charges relate mainly to visits to primary care facilities and emergency department visits. The total value of these user charges, after the doubling in levels that occurred in 2012, is less than 2% of total funding of the health system. More than 55% of the population are exempted from payment.

Turning to expenditure on long-term care; the OECD estimated that in 2010 Portugal only spent 0.1% of GDP in this area.[1] As described in Chapter 5, long-term care has traditionally been provided by families and charities in Portugal with the state only recently developing a network of providers (the RNCCI). Responsibility for public funding of long-term care and social care is divided between the Ministry of Health and the Ministry of Solidarity and Social Security. The Ministry of Health pays for palliative care both in hospital and at home. The two Ministries share the costs of medium term rehabilitation and long-term care, with a co-payment made by individuals based on their income or the household income. Social care, where it is provided, is paid for variously by the Ministry of Solidarity and Social Security, municipalities, charities and the individuals themselves.

It is not possible to obtain detailed figures for expenditure on these different elements. Moreover, comparisons are difficult because not all countries have reported expenditures and there may be some differences in definitions. However, all the indications are that long-term care expenditures in Portugal are below the average of other countries. Analysis of the percentage of total health expenditure annually which was spent on long-term nursing care between 2003 and 2011, for example, shows Portugal reporting much lower – by factors of 5, 10 and even 20 times – than other western European countries. [2]

FUTURE TRENDS

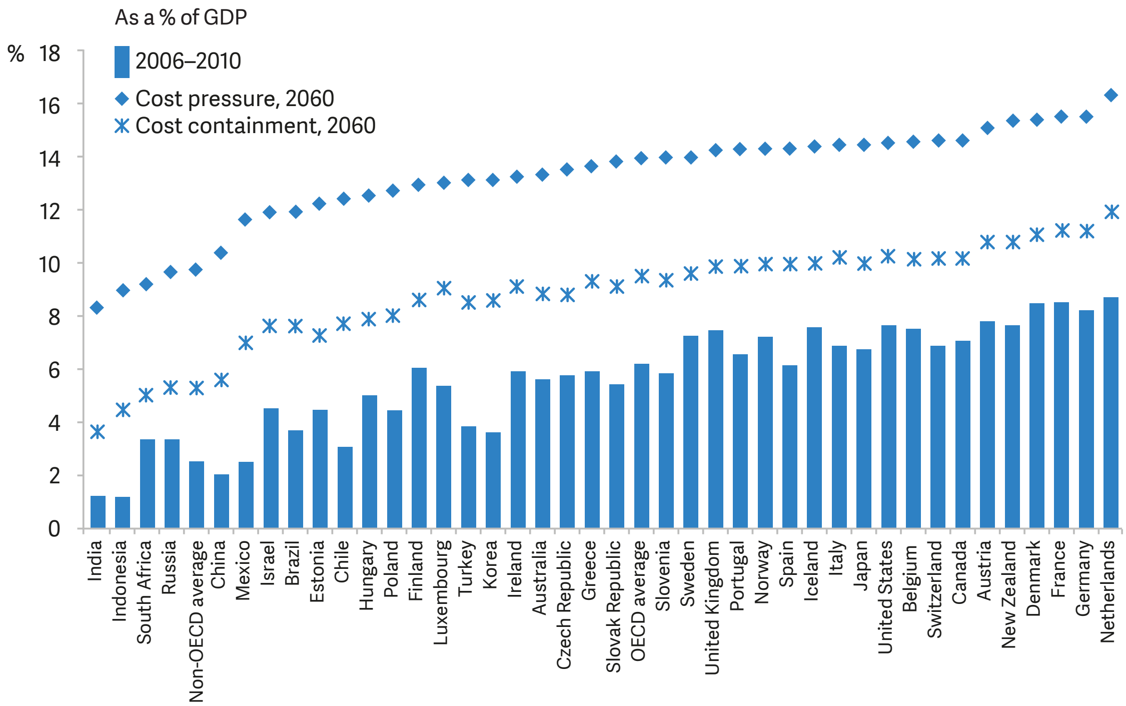
Until recently, all expenditure trends have been upwards; however, this has changed in the last 3 years. Data for 2011 and 2012 show expenditure is now level or declining across OECD countries.[3] It is too early to tell whether this is simply the result of unsustainable short term measures or a genuine and long-term change in trend. Whatever, the position, analysis of recent trends is informative.

The OECD's 2013 report *What Future for Health Spending?* offers a projection of public expenditure on health and long-term care between 2010 and 2060 based on the previous 15 years.[1] It deals with both health and long-term care and includes only the amount paid from public funds. In Portugal, this amounted to about 7% of GDP in 2010, with long-term care only accounting for about 0.1% of GDP.

The study shows that from 1995 to 2009 public expenditure on health and long-term care grew on average about 2% faster than GDP each year in OECD countries. It estimated that only around 0.5% came from the growth in the elderly population. The far larger element came from what it called *drift* – a mixture of increased use of technology, price increases and policy and institutional initiatives. In many European countries this *drift* is in significant part accounted for by governments explicitly investing in health during this period, higher staffing costs which are reflected in pricing and greater use of newer technology.

The study presents two scenarios: a *cost pressure* scenario, which is simply the continuation of current trends, and a *cost containment* one based on the assumption that policy action is taken to curb pressures on expenditure. Figure 3 shows these projections for OECD and BRICS countries. Portugal is near the OECD average and projected to have an increase in public expenditure on health from about 7% of GDP at the current time to about 10% on the *cost containment* scenario and to 14% on the *cost pressure* one in 2060.

Figure 3 · **Total public health and long-term care expenditure ratio to GDP**



Source: OECD – *What future for Health Spending?* 2013

This analysis based on figures up to 2010 would suggest that Portugal is facing cost pressures each year amounting to 2-4% above inflation on its public expenditure on health and long-term care depending on which of these scenarios is followed. This amounts to additional spending of between 120 and 170 million Euro a year at today's prices every year. Such projections should, of course, be treated with caution; not least because of the recent levelling off and falls in expenditure. They do, however, show the important impacts of government policy, staffing costs and technology on expenditures. All of these need to be managed very carefully.

SUSTAINABILITY

The non-financial conditions for sustainability were described in Chapter 1 as being about building the resilience of citizens and society, creating a fit for purpose and efficient health and care system, and having adequate numbers of well trained staff. Whilst there is not a precise definition of the financial sustainability of a health and care system, the key issue in a country like Portugal, which is heavily reliant on a public health system, is whether funds raised from taxes and other contributions can cover expenses.

The first point to note is that the population through its politicians has choices about what activities and outcomes it wants its health and care system and how much it is prepared to pay for this through taxes and other contributions. The Commission has not taken any view on what this amount might be, but used the working assumption that the goal is to maintain current levels of expenditure of around 10% of GDP with about 7% coming from taxes whilst upholding the founding values of the SNS – to secure equitable access to high quality services for all – and achieving the same or better outcomes and services. It should be noted that these figures are not targets or limits and that the key issue here is not the amount spent but the value achieved by that spending.

Others will no doubt argue for greater or lesser levels of expenditure and for changing the sources of funding so that, for example, taxes are increased or individuals pay more. This issue is addressed later.

It is worth noting, although this is not explored in this report, that there are important linkages between health and prosperity – a healthy population and the health sector make significant and multiple contributions to the economy and growth in the economy will increase the amount available to spend on health. Ill health affects productivity and increases social security payments, whilst good health can improve productivity. Moreover, health-related industries can, as argued by Health Cluster Portugal, contribute substantially more to the economy than they do today.[4]

It is difficult to make projections on how investment in health is likely to improve the economy; although some aspects such as reductions in working days lost to sickness or number of jobs created can be quantified. Nevertheless, increasing the impact that good health has on other sectors and on the economy in total should be a policy objective for the whole of government.

The immediate emphasis needs to be on managing expenditure and controlling costs whilst maintaining or improving outcomes. In the last 3 years Portugal, in common with other European countries, has reduced expenditure. This has been achieved mainly through reducing staff and pharmacy costs and increasing user fees. At this stage, it is too early to tell how much of these prove to be true long-term efficiency gains rather than simply cost-delaying short-run savings.

The Commission agrees with a 2013 report from the World Economic Forum on sustainability when it says:

> *"Much of the current debate on the future of health is characterised by short-term and siloed thinking and entrenched positions. A short-term view encourages solutions that deliver immediate results and discourages conversations about more fundamental changes that might only bear fruit in the long-term. A lack of cross-stakeholder dialogue constrains the finding of solutions outside the traditional approaches to healthcare."* [5]

Longer term sustainability will come from two sources:

- Tackling the underlying issues which have been the subject of so much of this report:
    a. Preventing disease and reducing the length of time people are ill
    b. Applying evidence effectively and using continuous quality improvement to help cut waste
    c. Changing the infrastructure of the health system

- The design and operation of the system

There is no single ideal model for a health system anywhere in the world; although European-style social solidarity models generally score higher than others in comparisons, as for example in the most recent Commonwealth Fund assessment which names the top 3 as the UK, Switzerland and Sweden in that order.[6] In the experience of the Commission, however, there are some key points to bear in mind when looking at the costs and efficiency of any system. These are shown in Figure 4. They are all variations on the theme of unnecessary use of health services or of market failures and reveal the importance of having a clear national framework to shape and develop the system in order to deliver care when and where it is needed. These points have influenced all the later discussion in this chapter.

Figure 4 · **Key points to avoid in health system design**

KEY POINTS TO AVOID IN HEALTH SYSTEM DESIGN

- Beware of *supply induced demand* – creating new services will increase demand whether or not services are actually needed – and even if the suppliers do not actively market the service
- Avoid *pay for service* schemes – which will incentivise activity rather than outcomes and drive up costs – this applies both to payments of individuals and to organisations
- Be careful about introducing any specific entitlements such as to regular check-ups – because these will be taken up, whether or not they are needed
- Be sceptical about "techno-optimism" – the belief that new technology or approaches such as *personalised medicine* will solve major problems – there will be costs and consequences

It should be noted here that whilst financial design alone will not be the salvation of the health system, poor financial design could ruin it.

THE PORTUGUESE SYSTEM

The Commission found virtually no appetite for completely changing the basic funding and financial arrangements of the SNS in any of the discussions with its stakeholders. There appears to be near universal agreement that the SNS should remain largely tax funded and available largely universally and equitably to the whole population. This broadly accords with the proposals from six reviews of health financing carried out over the last 22 years. The relevant results from these reviews are summarised in Appendix 7.

Given there was so little support for radical change in funding, the Commission has not reviewed alternatives such as moving to a completely private system but noted that this would be very expensive to institute and would have uncertain benefits. Several stakeholders, however, wanted to make the system into more of an open market, others wanted to increase charges for patients whilst others expressed directly opposite views on both these points. Many also advocated the need for improvements in financial management and the allocation of funds. Others drew Commissioners attention to regional differences in funding and provision. The Commission therefore decided to focus this part of the report on four sets of issues:

- Sources of funds
- Prioritising, planning and purchasing services
- Competition, choice and the private sector
- Governance, accountability and financial management

All of these suggestions, of course, would need to be implemented alongside the investment in health promotion, disease prevention and Public Health discussed in earlier chapters.

SOURCES OF FUNDING

There are three main ways to bring more money into the health system – from taxes to pay for the SNS; through co-payments and user fees; and from subsystems and private insurance systems. These are discussed in turn.

As was shown earlier, a smaller proportion of health and care expenditure comes from public funds in Portugal than in most other European and OECD countries. However, the Commission recognises that there is no scope for raising general taxes to increase expenditure in the foreseeable future and has not considered this option.

The Commission notes, on the other hand, that there is considerable scope for further taxes on unhealthy products which would not only raise revenue but help to improve health. Some are already in existence but higher taxes could be placed on alcohol and tobacco – the single biggest contributor to disease in Portugal – and Government should also consider minimum alcohol pricing, taxes on soft drinks with high sugar content, unhealthy food ingredients and on pollution from vehicles and other sources. The Commission is not making a recommendation on the levels of tax on these items but believes that the proposed National Health Council should consider these issues and advise government accordingly.

There is also scope for providing financial incentives through the tax system for healthy behaviours. A number of countries now link social security benefits to health seeking activity such as ensuring children are vaccinated or that pregnant women attend ante-natal classes. It seems likely that these "conditional cash transfer" policies and other tax incentive schemes will be an increasingly prominent policy feature globally over the next 25 years. The proposed National Health Council might also want to consider this, perhaps with the proposal that some of the money raised through higher taxes on things that damage health should be used to fund incentives for healthy behaviour as happens in some other countries.

The Government might also want to consider identifying a proportion of its general tax revenue specifically for health. This might have the advantage that it would show citizens how much they were paying for their health system. There is no good evidence as to whether this visibility of costs would have any effect on peoples' behaviour so the Commission has not taken a view on this. It does, however, note that it would not be a good idea to tie health funding to a specific proportion of GDP because this can vary significantly year to year.

Table 1 analyses the funding structure in more detail, revealing some of the complexity of the system. It shows that SNS funding is only a little over half of all funding, and that "out-of-pocket" spending – mostly on co-payments in the SNS - is around 30%. Private insurance, either voluntary private insurance or private health subsystems – health insurance provided by large companies, in some cases including a component of health care provision as well – accounts for less than 6% of total funding, even though the Portuguese Insurers Association claims to cover more than 2.2 million people with some sort of health insurance.

Table 1 · **The funding structure of the Portuguese health system** [7]

	2000	2006	2011
Private insurance	1,36%	2,37%	3,22%
Private health subsystems	2,17%	2,40%	1,85%
Other private funding	0,72%	0,56%	0,64%
National Health Service	57,88%	53,56%	54,00%
Public health subsystems	5,91%	6,84%	3,75%
Other public funding (includes fiscal credits)	4,40%	6,30%	3,52%
Private spending from households	26,3%	28,63%	31,65%
Social Security	1,20%	1,16%	1,38%

Source: INE, Conta Satélite da Saúde.

Earlier discussion has shown that Portuguese people already pay high levels of health care expenditure from their own pockets. This expenditure has been increasing over time. User fees doubled in 2012 and the recent reduction in fiscal benefits associated with private health care expenditures has further increased co-payments in 2012 and 2013. This suggests that it is difficult to consider further increases.

There are two potential roles for co-payments. The first is to control frivolous or abusive use of health care services. The second one is to fund health care provision. Evidence from around the world is that facing a cost at the time of accessing health care reduces both appropriate and inappropriate usage and has a negative effect on the health of the poorest in society, who are often the sickest. [8, 9] Co-payments are generally regressive in nature.

There are also major drawbacks to using co-payments to raise expenditure as they raise very little in practice. If the co-payment is high, there have to be high levels of exemption and those who can afford it may opt to pay for private insurance. If it is low, it raises little money when the administrative costs of collecting payments are taken into account.

> Earlier discussion has shown that Portuguese people already pay high levels of health care expenditure from their own pockets. This expenditure has been increasing over time.

These relatively high levels of out-of-pocket expenditures mean that there is a higher risk of families facing catastrophic health care costs which bring them below a defined poverty line and their whole livelihood and future is affected. This risk has reduced substantially over time, but there is still a risk of more than 1 in 20 that health costs will force some people into poverty and have a catastrophic effect on the poorest people. [10]

The other major source of potential extra funding is from subsystems and insurance schemes. Table 1 above has shown that they account for 5.6% and 3.2% of funding respectively. Subsystems in Portugal provide cover for specific groups of employees. They were created before the SNS and were not dismantled when it was started. They are part-funded by the employee and by the beneficiary. Until May 2014, the largest subsystem which looks after civil servants, the ADSE, received a subsidy from the Government. This has now been removed and beneficiaries pay the full cost. The main advantage to the individual from these subsystems is that they can go directly to the private sector and to specialists for payment of a small fee, with no gate keeping. The evidence available so far suggests that this translates into more use of resources rather than into better health status as self-assessed by patients.

Subsystems and insurance schemes do bring more money into healthcare; however, by their very nature, subsystems are only available to employed people and insurance schemes are only available to people with enough money to pay the premiums. The bigger health problems lie with older and poorer people who may well not be in employment and could generally not afford the cost of private insurance. The Commission does not therefore advocate promoting subsystems or private insurance as a way to increase funding significantly and improve the service.

PRIORITISING, PLANNING AND PURCHASING SERVICES

Many aspects of planning have already been dealt with in earlier chapters. There is now a record of producing four year National Health Plans which set out priorities and policies. The Commission believes that more emphasis in future versions should be given to achieving sustainability through the three areas identified above:

a. Preventing disease and reducing the length of time people are ill
b. Applying evidence effectively and using continuous quality improvement to help cut waste
c. Changing the physical and staffing infrastructure of the health system

This would involve adopting the many new and developing approaches described in earlier chapters such as the model for chronic disease management discussed in Chapter 5 and the widespread use of continuous quality improvement described in Chapter 4.

The Commission has also proposed in Chapter 5 a simplification of the overhead structures in the health system and clarification of governance and accountabilities. This must include clarification and improvement in the way services are planned and purchased. Over recent years, Portugal, like other countries, has created a split between those who plan and commission or contract for services and those who provide them. These arrangements needs to be continually developed as do the skills amongst staff for commissioning, purchasing and contracting health services. The ADSE subsystem has been moved to the Ministry of Health and internal discussions on how to integrate it are under way. This provides a promising opportunity to use its expertise in association with the SNS in the future.

The Commission heard many complaints about the way funds have been allocated on an historical basis which did not recognise regional differences and changing needs. It noted that the basis for allocation is beginning to be moved towards a needs based or weighted capitation basis and believes this is the right direction for the future.

Much of the development of planning and purchasing services internationally is focused on developing outcomes and value based purchasing and on identifying and using the most appropriate units of measurement and associated incentives. Both these approaches, which overlap, are concerned with contracting and paying for services from providers based on outcomes or the implementation of best practice or on achieving a pre-defined level of value.

Portugal has begun to develop an approach based on rewarding best practices for some highly specialised services. This "comprehensive pricing" relates to five or six procedures, for which particular quality indicators must be met in order for hospitals to receive bonuses. This is a similar approach to that adopted in England where providers don't get a bonus for applying best practice but, instead, only receive 90% of the price if they don't apply best practice. This has the effect of making it clear that best practice should be the norm and failure to achieve it should be penalised.

The English NHS has also begun using patient-reported outcome measures (PROMs) to supplement existing measures of quality and performance improvement. PROMs are a series of structured questions that ask patients about their health outcomes after treatment from their point of view. Since 2009, the English Department of Health has required routine measurement of PROMs for four surgical procedures, but work is underway to extend these to chronic conditions including diabetes, stroke, COPD and asthma. The English NHS aims to measure everything it produces in terms of *health gain* and outcomes rather than in terms of the production of *health care* and activity levels.[11] Patient reported outcomes, in other words the patient's assessment of the success of the treatment, will be a vital part of this.

Professor Michael Porter from Harvard Business School has is using the notion of value based health care, to think about the planning and delivery of health care at the organisational level. His team are engaged in undertaking the research necessary to define outcomes and value.[12] He argues that in any industry, performance and accountability depend on having a shared goal – but in healthcare, stakeholders have myriad, often conflicting goals (including access to services, profitability, high quality, cost containment, patient centeredness and so on). A lack of clarity about these goals has led to slow progress in performance improvement. Instead, Porter argues that achieving high value for patients must become the overarching goal of healthcare delivery – with value defined as the health outcomes achieved per x amount spent. This goal matters for patients, unites the interest of all actors, and should define the framework for performance improvement.

This approach can be seen to work well for patients with a single problem, a hip replacement for example, but has been criticised for not dealing adequately with patients with co-morbidities and complex conditions. It can also lead to an over-emphasis on specialities and acute treatment and underestimate the importance of more general care and, of course, prevention. The ultimate tests will be how well this specialist focus can be integrated with generalists and how well it can reflect patient values such as increased independence and quality of life.

Portugal has the advantage of still having generalists in internal medicine in SNS hospitals; whilst their equivalent "hospitalists" are being re-invented in

America and elsewhere. Evidence suggests that the best care is provided by generalists working in close liaison with specialists and as part of wider multidisciplinary teams which engage patients and carers. With generalists in primary care and in hospitals, Portugal is as well placed as anywhere to develop effective ways of linking this vertical specialist approach with the horizontal integration of services around the patient discussed in Chapter 5.

These approaches are designed to incentivise the use of best practice and depend on good measurements of the right things at the right time. At the moment in Portugal, as elsewhere, measurement is often poor and the units used for measurement and payment may promote perverse incentives. Efforts are being made to ensure that payment systems reflect developing and best practice so, for example, a provider can be paid for a telemedicine consultation not just for a face to face one. However, the system is in transition. The most egregious example of a perverse incentive described to the Commission concerns hospital acquired infections. At the moment a provider will be paid for the original reason a person was admitted to hospital, an operation for example, and additionally for treatment of an infection acquired in the hospital. This needs to be corrected so that the provider bears the cost of an infection contracted in the hospital and of any other avoidable complications.

> The English NHS has also begun using patient-reported outcome measures (PROMs) to supplement existing measures of quality and performance improvement.

There are similar considerations in primary care. As was noted in Chapter 5, only half the country is covered by the new arrangements and, therefore, only half of primary care is operating on the basis of service contracts. These need to be continuously updated to provide greater incentives for prevention and the holistic care of the patient and to remove any perverse incentives.

Outcomes and value based purchasing for health care are not yet fully developed or being applied at scale. However, they show promise as part of a wider development to make sure that evidence is applied systematically and patients' experiences and perceptions are taken fully into account. The Commission believes that Portugal should, therefore, continue with its development of outcome and value based purchasing and with developing appropriately flexible ways and units for contracting. It should stay in touch with and contribute to the development of good practice globally, but should not expect enormous benefits in the short term. These developments should follow service changes and reinforce and incentivise best practice.

These arrangements will, over time, reward good performers and penalise poorer ones. Efforts will need to be made to bring the poorer performers up to standard. However, these new purchasing processes, together with the move of more service delivery into homes and communities will mean that some hospitals will fail. There are particular problems where these are in the public sector because there are no existing mechanisms for identifying and managing failure and, where necessary, replacing the management, closing some services, merging it with another more successful hospital or, in the last resort, closing it. These will need to be developed and implemented, otherwise Portugal will continue to pay for unnecessary and/or poorer quality duplicated capacity.

COMPETITION, CHOICE AND THE PRIVATE SECTOR

Competition in health and care systems can take place at two different levels: competition between insurers and competition between providers. There are examples of both in different countries and some countries have introduced competition very recently. The Netherlands, for example, in 2006 appointed five private insurance companies to use public funds to commission services in competition with each other. Patients can sign up with any of the five funds, although they are based in the five different regions of the country. England introduced competition both between NHS organisations and with private sector providers in 2002. All the countries which have competing insurers, including the Netherlands, USA and Switzerland, also have competition between providers.

Turning first to competition between insurers, there is an international study which has analysed the preconditions that need to be in place for competition at the insurance stage to lead to efficient outcomes. van de Ven et al propose ten preconditions for competition and assess whether such conditions are fulfilled in five countries.[13] The ten preconditions are 1) free consumer choice of insurer; 2) consumer information and market transparency; 3) risk-bearing buyers and sellers; 4) contestable markets – easy entry and exit; 5) freedom to contract and integrate; 6) effective competition regulation; 7) cross-subsidies without incentives for selection; 8) cross-subsidies without opportunities for free-riding; 9) effective quality supervision; 10) guaranteed access to basic care.

The overall conclusion of van de Ven et al is that after more than a decade of pro-market reforms, some aspects in the preconditions are still far from completion, namely information to consumers on quality of care. Effective quality supervision is still an important challenge. Even conditions like easy entry and exit and effective competition regulation are only in place in one of the five markets (The Netherlands), which has also faced an increase in costs of health care.

The Commission noted that introducing competing insurers like this carries a very large set up or "dead weight" cost from the dismantling of existing systems and the creation of new infrastructure – in England in 2000 this was estimated at £1 billion – and has uncertain benefits. The recent introduction of this in Netherlands should be studied. However, experience to date there has been that whilst unit prices for procedures have gone down, overall volumes and total costs have gone up. There is no evidence yet of the impact on health outcomes.

Competition between providers is rather different. Firstly, Portugal has long had competition in the sense that individuals can choose to supplement SNS provision by going to private providers either via subsystems or by paying privately. The vast majority of parents, for example, choose to take their children to private paediatricians even though they have access to, often the same, paediatricians through the SNS. Table 2 shows that the public sector only accounts for a little over 40% of provision of health services whilst the private sector accounts for almost 60%. This table needs some interpretation: most of the private sector consultations are in the specialities of cardiology, dentistry, gynaecology and ophthalmology and a significant proportion of the other costs of the private sector provision is expenditure on pharmaceuticals.[14]

Table 2 · **The public/private mix of funding and provision in 2011**

		Funding	
		Public	Private
Provision	Public	39,53%	1,68%
	Private	26,00%	32,79%

Source: INE, Conta Satélite da Saúde.

There is evidence from around Europe that competition between existing providers can lead to improvements in quality and waiting times for elective services. Offering patients information about quality and giving them choice of provider in these circumstances can provide benefits. In practice, relatively few patients travel any great distance to an alternate provider and the impact is mainly on the way the providers behave. The threat of competition is often as effective as competition itself.

However, for services which require continuity of care and the engagement of different providers, cooperation and collaboration can be damaged by the fragmentation induced by competition. Here the evidence suggests that it is far more appropriate to develop networks of care linking across providers.

Moreover, the way in which competition is used is important as two examples from Portugal show. The proper use of instruments is essential for effective competition to deliver the expected results. An example comes from the competitive tendering for pharmacies inside hospital grounds. Using auctions to have competition for the market is a mechanism that is usually associated with good outcomes. In this case, the unrealistic bids by some candidates were not discounted in the assessment of proposals (like offering a margin to be paid under the contract that is larger than the regulated margin allowed in the prescription-only pharmaceuticals), and after some time the inability to financially sustain the business led to bankruptcy and closure of these cases. This has been presented sometimes as failure in the use of competitive mechanisms. At the opposite end of demonstration that competitive forces have benefits, the measures after October 2010 in the pharmaceutical market created a downward trend in generics' prices by competition alone. The usual saying that "the devil is in the details" applies to development of effective competition situations in health care systems.

This all suggests that Portugal should support a pragmatic and evidence-based approach which advocates using competition in a range of areas where it is shown to be effective whilst building collaborative networks in others. These separate areas can be defined. Patients should have information about different services and networks and the power to choose which to use – however, we should not make great claims for the impact of this sort of choice but, rather, advocate as in earlier chapters for greater patient involvement in choice and decisions about treatment in the discussion with clinicians. The Government should also be careful to ensure that this provision of information is objective and not seen as an opportunity for providers to market services – and increase supply-driven demand for health care. At the same time, the Ministry should continue to evaluate the evidence coming from other countries and react accordingly.

Competition for SNS funding with the private sector opens up other questions. As can be seen from the figures above, there is already extensive use of the private sector for delivery of services. This opens up the potential for conflicts of interest for organisations but also for individuals working in both sectors. There are

> (…) Portugal should adopt a pragmatic and evidence-based view, engaging the for-profit and not-for-profit private sector in its mission to provide high quality services for everyone where this makes sense and not where it does not.

long standing rules for managing this. The Commission believes, as described in Chapter 5, that it is imperative to have a broader framework or public/private concordat which would include these rules and regulations but also set out the conditions under which SNS funding may be spent in the private sector and spell out the requirements of transparency for organisations and individuals.

The Commission's view is that here, as with competition, Portugal should adopt a pragmatic and evidence-based view, engaging the for-profit and not-for-profit private sector in its mission to provide high quality services for everyone where this makes sense and not where it does not. Where the private sector is engaged in this way it should have the same requirements for quality, transparency and date collection as the public sector and espouse the same values.

GOVERNANCE, ACCOUNTABILITY AND FINANCIAL MANAGEMENT

Discussion in earlier chapters has stressed the importance of governance and accountability making the points that:

- The public need to be better informed about services and costs
- Ultimately the population through its politicians needs to decide how much they want to spend on health and social care and on what the priorities are
- There need to be appropriate governance arrangements at each level of the system to engage stakeholders, including citizens, and secure transparency and accountability

These governance and accountability arrangements are crucial in securing good financial management. In addition, the Commission makes two further recommendations, designed to improve efficiency and financial management, on creating an SNS Stabilisation Fund and establishing independent value for money audit.

Planners and health care units in the SNS need stable funding to be able to plan and deliver services and to make service changes which will inevitably span financial years. Funding is currently allocated annually but, as Table 3 shows, actual spend and budgeted spent are often very different and there are transfers made between the Treasury and the SNS within years.

There are conflicting pressures here. Pressure to contain Government deficits translate into budget cuts in the SNS in years of economic downturn. At the same time, management of SNS care delivery is moving toward entrepreneurial rules, meaning the creation of strategic plans and management accountability. This is hard to reconcile with major yearly changes in available budgets. Thus, a different mechanism to have predictable funding to the SNS is required. A suggestion is to create a SNS stabilization fund, with very clear and strict rules, that may receive a GDP-related contribution every year but has to manage fluctuations by accumulating assets during the high-growth periods, to be used in low-growth periods to stabilize the SNS budget.

A similar-in-spirit mechanism exists with respect to public pensions, the *Fundo de Estabilização Financeira da Segurança Social*. A possible way of setting this would be to set a path for future spending in health care (limits to spending), revised yearly the path for the next five years; this path should be made consistent with the strategic plans of SNS institutions and budgets allocated; then the Government budget transfers to the SNS are contributions to a SNS stabilization fund, from which the SNS budget is collected. The transfers can be set as a percentage of trend/potential GDP (not actual one) plus some small discretion margin. The rules of constitution of the fund and its management and use need to be clearly defined, to avoid opportunistic behavior by the Government (reducing transfers to force use of the fund, for example).

Table 3 • **Budgets and expenditures of the SNS: 2006-2014**

	SNS budget	Budget spending execution (source: DGO)		
	Initial budget	SNS transfer	Total revenues	Total spending
2006	7636,7	7631,9	7673,4	8031,2
2007	7674,8	7673,4	8241,1	8131,6
2008	7900,0	7900,0	8395,5	8519,0
2009	8100,0	8200,0	8708,6	8925,3
2010	8698,7	8848,7	9167,9	9527,7
2011	8140,0	8251,8	8583,9	8859,1
2012	7498,8	9735,5	10136,3	8275,1
2013	7801,2	7837,6	8325,2	8325,2
2014	7582,1			

Note: 2013 and 2014 Government projections. After 2010 includes spending no longer invoiced to public subsystems (ADSE, MAI, MD), in the amount of 548,7M€

Financial management could also be improved by better arrangements for scrutiny and audit. There is currently no regular review of the performance of SNS units or services in terms of value for money. Such reviews would consider whether a service has made the optimal use of resources to deliver the planned outcome and avoided waste, duplication and the use of unnecessarily expensive materials or procedures. Each such review would focus on a particular topic, for example, infection control or breast surgery and look across the SNS at whether services were providing value for money in terms of delivering against guidelines and doing so in an efficient manner. There are models for these audits in England, where this is done by a government agency that reports directly to Parliament, and in other countries which could be adapted for Portugal.

The Commission noted in Chapter 4 that several national bodies currently have some oversight of quality and has proposed that this be simplified as part of the proposed review of overheads. A health body could have responsibility for these audits as part of its wider roles. However, the Commission recommends that these audits should be undertaken by a body independent of both the Ministry of Health and the Treasury which should report with recommendations to the Parliamentary Health Committee and to the National Health Council.

TRANSITION COSTS

The Commission has considered the costs of implementing this report and managing the changes proposed here.

A number of the Commission's recommendations will add additional costs in the short term because they relate to new organisations, appointments and activities:

- the establishment of the National Health Council
- the creation of SNS Evidence and the agency for quality improvement and implementation
- the appointment of a Chief Nursing Officer
- the management of the SNS Stabilisation Fund and the value for money audits

The Commission's view here is that these initial costs should be met from the 25%+ savings to be made as part of the review of accountability and overheads proposed in Chapter 5. Over time, however, all these activities should generate efficiencies and/or release funds.

A number of other recommendations are for strengthening or developing existing activities which are already at least part funded:

- the campaign on health literacy
- the development of the *Portal da Saúde* and Electronic Health Record
- the strengthening of public health

These, too, will create efficiencies in the longer term. Any short term investment in these areas will need to be made as part of the Health Ministry's normal planning process. However, the possibility of part funding from other ministries and sources should also be considered as part of their commitment to including health promotion in their policies. In Germany, for example, there is currently discussion about whether social insurance schemes should contribute to health promotion and disease prevention and other activities. There should also be, as noted earlier, funding from taxes on unhealthy products and practices.

The biggest new costs will undoubtedly come from the need to invest in the community – in long-term care, primary care, palliative care and elsewhere. In principle much of this investment should be able to come from reductions in hospital costs. The Commission recognises that there will undoubtedly be delays in releasing funds and that there will inevitably be a period of "double-running" when community based services are duplicating hospital based ones.

In these circumstances the Commission recommended in Chapter 1 that the Government creates a transition fund to help manage the change. This will be need to be very tightly managed – with good business planning and project management – but should in the longer term be the most efficient and cheapest way to manage the vital transition that needs to take place over the next 25 years.

FUTURE FUNDING NEEDS

Discussion earlier in this chapter showed how, based on figures up to 2010, Portugal might be facing cost pressures each year amounting to 2-4% above inflation on its public expenditure on health and long-term care or between 120 and 170 million Euro a year. However, expenditure has fallen in the last 3 years so cost growth may be less in future.

The purpose of the sustainability strategy proposed here is to tackle health need, release funding from existing services and slow future growth in funding. The potential for releasing resources by the sort of approaches advocated here appears to be significant. The Calouste Gulbenkian Foundation has agreed to provide some funding for three *Gulbenkian Challenges.* These are described in more detail in Chapter 9. Two of these will begin to release costs in the next 5 years. The Commission has made an estimate of the likely financial benefits from this which can serve as an indicator of the levels of funding that can be released through this wider sustainability strategy.

Taking each of these in turn:

- The **Infections Challenge** of halving current rates of hospital acquired infections could save up to Euros 140 million a year. A widely quoted estimate of the number of additional days in hospital caused by these infections suggests that the total cost each year of these infections is about Euro 280 million.[15] The majority of this saving would be available as soon as the rates of infection were cut.

- The **Diabetes Challenge** of preventing 50,000 people getting diabetes could save increased costs of 45 million Euros a year after 5 years and, assuming that the programme is continued thereafter, a further 18 million cumulatively each year thereafter. This is a conservative figure based on taking half the estimate in the Annual Report of the Diabetes Observatory that each person with diabetes costs about Euro 1800 each year but recognising that not all this money can be saved and that the higher costs are likely to be met in later years as the person ages and complications progress.[16]

- The **Children's Challenge** of Portugal becoming a leader in children's health and well-being will have an effect in the longer term. Extrapolation from an American study and taking a very conservative estimate of savings (1/3 of what the American study would calculated) would suggest that prevention work with children aged 0 to 5 would save Euro 80 million each year over the lifetime of this cohort.[17]

The future is, of course, uncertain and Portugal, in common with other countries, will face many new and unknown challenges in the next 25 years. The Commission believes that the best way to try to secure a high quality and sustainable health system which maintains the founding values of the SNS is through the approach advocated here. The Gulbenkian Challenges mirror this approach and, as can be seen above – whilst the precise figures shown here should be treated with some caution – have the potential to make a very significant contribution to this.

CONCLUSIONS AND RECOMMENDATIONS

The Commission has taken a long-term view about financing, sustainability and value achieved from the health system. In this context the various financial and management mechanisms discussed in this chapter will help control costs. However, major impact will only come from changes in practice within the health and care system itself. The Commission therefore proposes two recommendations that will help make these changes and deliver these benefits.

Figure 6 · **Recommendations**

RECOMMENDATIONS

19. **SUSTAINABILITY STRATEGY.** Adopt a sustainability strategy to improve quality and reduce costs based on:

a. Targeting three main areas for change:
  - Reducing morbidity preventing disease and reducing the length of time people are ill
  - Applying evidence effectively and using continuous quality improvement to help cut waste
  - Changing the infrastructure of the health system

b. Continuing to develop the commissioning and contracting process: focusing on outcome measures; keeping international experience of competition and market based methodologies under review; and ensuring it is flexible enough to meet the demands of constantly developing services with new methods and channels of delivery.

20. **FINANCIAL MANAGEMENT.** Improve financial management alongside the introduction of improved governance and data availability and the strengthening of accountability. This should include the creation of a rolling 5 year SNS Stabilisation Fund, which will aid planning, and the introduction of independent value for money audits which will report to Parliament and to the proposed National Health Council.

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Recommendations

8

The Commission has made seven groups of recommendations designed to set Portugal on the path towards creating a high quality and sustainable health system for the future.

CHAPTER 1

VISION FOR THE FUTURE – A MAJOR PROGRAMME OF CHANGE

1. **A new compact for health.** A new compact for health should be established which describes the new relationships and roles needed in the transition from today's hospital-centred and illness based system, where things are done to or for a patient, to a person-centred and health based one where citizens are partners in health promotion and health care.

2. **National Health Council**. The National Health Council should be established as a whole of society alliance which should own and develop the Compact for Health and refine the vision for the future, take an overview of the system and advise on policy in line with this vision. It should be representative of citizens and all sectors of society and independent of politics and report to Parliament, the Minister of Health and the public.

3. **SNS Evidence**. SNS Evidence should be created as a new agency, which brings together the existing programme of clinical guidelines with a new process for assessing new technologies and therapies, and ensures that evidence is available everywhere within the system at all times. The agency should make its deliberations and findings open to the public so that they as well as clinicians are able to see the evidence.

4. **Transition Fund**. A transition fund should be created that can help support the costs of "double running" and the other interim costs of developing a health system with better chronic disease management, more services in the home and local community and specialist networks reaching all parts of the country.

CHAPTER 2
ACTION BY CITIZENS

5. **Health Literacy.** There needs to be a new cross-government national programme for health education and health literacy which will equip citizens in practical terms to stay healthy and, when ill, share in decision-making. This should be very high profile and led by an independent group of Ambassadors, including people from the media and communications, who would report to the Ministers of Health and Education.

6. **Ownership of personal health information.** High priority needs to be given to implementing fully the Electronic Health Record as the essential underpinning of an integrated and high quality service and giving citizens ownership of all the health information held about themselves whether in an electronic form or otherwise.

7. **Access to information.** There needs to be a single authoritative source of information available to citizens, perhaps built on the *Portal da Saúde*, which would cover information about health, disease prevention, and services and their quality. Health organisations should be placed under an obligation to provide an agreed range of data for this purpose and regulators should ensure that citizens have this access.

8. **Representation.** The Ministry of Health should appoint lay people, able to represent the perspective of citizens and patients, to the boards of all health bodies where it has the right to make appointments.

CHAPTER 3
ACTION ACROSS SOCIETY

9. **Municipalities.** Municipalities, which already play leading roles in the well-being of their populations, should include health and health organisations in their local social welfare partnerships to support cross sectoral planning and working**.**

10. **Civil society**. Municipalities, health and commercial organisations and the appropriate ministries should work together to find better ways to promote, support and engage voluntary organisation and informal networks of care at all levels of the health system.

11. **Public health.** The Government, relevant Ministries, the SNS and public health institutions and associations should work together to strengthen public health functions across the whole health system at all levels, with knowledge of and expertise in public health becoming a larger part of every health worker's education and training. Consideration should be given as to whether new legislation on Public Health is needed to support these recommendations.

CHAPTER 4

THE CONTINUOUS PURSUIT OF IMPROVED QUALITY AND THE APPLICATION OF KNOWLEDGE AND TECHNOLOGY

12. **Continuous quality improvement.** All partners in the health system from the Ministry and citizens to SNS bodies, municipalities, universities and industry need to ensure that the approach of continuous quality improvement is adopted throughout the system as a means both of promoting quality and of ensuring that new scientific and technological advances can be systematically integrated and implemented everywhere. Expertise in quality improvement needs to become part of every health worker's education and training. This should be supported by a new expert agency able to promote quality improvement, identify and spread good practice and support implementation. It should work with health and other bodies to create and confirm shared methodologies for quality improvement and implementation; facilitate training and be able to offer advice and support as necessary. This needs to be accompanied by standardisation of accreditation processes and of data collection and reporting.

13. **SNS collaborations with research and industry**. SNS, research and industry leaders should set up collaborations in a small number of locations around the country to work together and with citizens on developing new practices, technologies and services.

CHAPTER 5

A PERSON-CENTRED AND TEAM-BASED HEALTH SYSTEM

14. **New models of care.** Policy makers, planners and providers need to work together to create services which provide integrated care for all individuals with particular emphasis on: chronic disease management; the development of more services in the home and local community; and the creation of spe-

cialist networks – based in reference centres but reaching all parts of the country through technology and shared protocols.

15. **Accountability and overheads.** Accountabilities need to be clarified across the whole system and there needs to be a review of the number and roles of the many national bodies associated with health and care, reducing their numbers and costs by at least 25% and releasing funds for investment elsewhere.

16. **Public private concordat**. A public/private concordat needs to be developed as a framework for the engagement of private providers in the SNS which safeguards the public interest whilst bringing potential new resource and innovation to the health system.

CHAPTER 6
NEW ROLES AND STRENGTHENED LEADERSHIP

17. **Professional education**. The Ministries of Health and Education should set up an inclusive process to review professional education in the light of current and future developments in health and ensure that it embraces the new needs for partnership with patients, quality improvement and public health.

18. **Nursing.** The status of nurses within Portugal should continue to be raised by appointing a Chief Nursing Officer, extending their roles and, as funding allows, increase their numbers. Following the introduction of the new family nurse role consideration should be given to extending the role of nurses and other professionals in other areas.

CHAPTER 7
FINANCIAL SUSTAINABILITY

19. **Sustainability strategy**. Adopt a sustainability strategy to improve quality and reduce costs based on:
    a. targeting three main areas for change:
        - Reducing morbidity preventing disease and reducing the length of time people are ill
        - Applying evidence effectively and using continuous quality improvement to help cut waste
        - Changing the infrastructure of the health system

    b. Continuing to develop the commissioning and contracting process: focusing on outcome measures; keeping international experience of competition and market based methodologies under review; and ensuring it is flexible enough to meet the demands of constantly developing services with new methods and channels of delivery.

20. **Financial management**. Improve financial management alongside the introduction of improved governance and data availability and the strengthening of accountability. This should include the creation of a rolling 5 year SNS Stabilisation Fund, which will aid planning, and the introduction of independent value for money audits which will report to Parliament and to the proposed National Health Council.

IMPLEMENTATION

The Commission believes that many of these recommendations can start to be implemented in 2015 and will begin to have an impact in Portugal in 2016. It has therefore suggested to the Calouste Gulbenkian Foundation that the Foundation should review progress in late 2016 and publish a report on this in early 2017.

It is delighted that the Calouste Gulbenkian Foundation will support the Gulbenkian Challenges described in Chapter 9 which will help develop the methods needed for successful implementation of these recommendations and begin the process of transition to a high quality and sustainable health system in the future.

The Gulbenkian Challenges

9

The approach described in this report demands more inclusive ways of developing policy, better processes of implementation and new systems for constant learning, evaluation and adaptation. It also requires everyone to play a role. The Calouste Gulbenkian Foundation has committed itself to playing its part by initiating three *Gulbenkian Challenges* which each exemplify this approach – showing what can be achieved – whilst tackling some of the most important challenges in Portugal.

A LEARNING ENVIRONMENT WHERE EVERYONE HAS A ROLE TO PLAY

It will take considerable time before the public feel the effects of the report's recommendations. The Calouste Gulbenkian Foundation has therefore decided to provide some initial funding for three *Gulbenkian Challenges*. These are three big, bold but achievable challenges that can show what can be done at scale across Portugal by using the approaches described here – and, as seen in Chapter 7, can have a significant impact on the sustainability of the whole system.

These *Challenges* are designed to support the SNS and the Ministry of Health with their important and demanding responsibilities. Each will address a major health concern, each will be highly visible to the public, each will be led by a different group and each will need professional as well as lay champions. They will help build energy and assist people in Portugal in seeing their health system not just as something that provides them with services but a something they own, participate in and can shape for the future.

They will also help create a learning environment for health in Portugal – where everyone has a role to play.

The Gulbenkian Challenges

The three *Challenges* are respectively:

1. An immediate and short term goal concerning hospital acquired infections, where Portugal has one of the worst rates of infection in Europe. The *Challenge* is for a group of SNS organisations to demonstrate that

they can halve the rate in their hospital in 3 years as a precursor to all organisations doing the same.

2. A mid-term goal concerning diabetes prevention, where Portugal has the highest prevalence of the disease in Europe. The *Challenge* will be to support the National Diabetes Association and partners to prevent 50,000 people who are at high risk of getting diabetes from contracting the disease in the next 5 years.
3. A longer term goal concerning children's health and well-being where, despite very low perinatal mortality rates, Portuguese children are unhealthier and have lower levels of well-being than many of their peers in other countries. The *Challenge* will be to bring together health and education leaders with partners from across civil society, industry and community to make Portugal a leader in children's health and well-being.

The 3 challenges are outlined in Figure 1.

Figure 1 • ***The Gulbenkian Challenges***

THE GULBENKIAN CHALLENGES

- Reducing hospital acquired infections – halving rates in 10 hospitals in 3 years
- Slowing growth in diabetes – preventing 50,000 people getting the disease in 5 years
- Helping the country become a leader in early childhood health and development – with measurable improvements in the health and well-being of children

The Infections Challenge

Hospital acquired infections are a matter of great concern to patients and affect both the quality of care they receive and the costs of their treatment. Portugal has currently one of the worst rates of infection in Europe. The Infections challenge of halving current rates of hospital acquired infections could save 280 million Euro a year according to Ministry of Health estimates. An alternative estimate, based on Fiorentino and Barros (2014), puts the possible savings at close to 340 million Euro a year. The majority of these savings would be available as soon as the rates of infection are cut. However, both of these estimates are based on costs of bloodstream infections, and there is some uncertainly as to how they relate to the costs of other common types of hospital acquired infections.

The Calouste Gulbenkian Foundation is proposing to support 10 hospitals around the country to achieve a much faster reduction of 50% in 3 years. This will be done through using the quality improvement methodologies described in Chapter 4 so that each hospital can learn from each other as well as from its own experiences in reducing infection rates. This methodology has been used successful in other countries – including both England and Scotland, where rates have been reduced by 85% and the issue is no longer of public concern.

It is envisaged that rapid progress in these hospitals can be followed by faster improvements in others as the methodology spreads and people see the results.

This *Challenge* will help Portugal reduce other infections and tackle anti-microbial resistance, making its contribution to the World Health Organisation and EU initiatives on these major global problems.

The Diabetes Challenge

The Diabetes Challenge is to slow the continuing rise in diabetes – the fastest growing health problem in Portugal. It is estimated that Portugal has the highest prevalence of the disease in Europe and that diabetes cost the health system in excess of 1,200 million Euros in 2011 or about 0.8% of GDP.[1] Each year around 60,000 people in Portugal are diagnosed – and then need care and treatment for the rest of their lives.[1] It is amongst the most pressing health issues to address in the country.

Diabetes needs to be tackled both through primary prevention – which concentrates, for example, on reducing the availability of unhealthy food and creating healthy environments – and through targeting the people most at risk. Both are essential. There is good international evidence about what can be done to prevent diabetes amongst people at high risk and in some cases reverse it. Studies have shown that it is possible to halve the growth in new cases of type 2 diabetes in 3 to 5 years through relatively simple evidence based interventions on diet and exercise.[2, 3, 4]

The *Gulbenkian Challenge* is to focus on people at high risk and reduce by 50,000 the number of people getting the disease in 5 years from 2015. At today's rate, about 60,000 people a year are diagnosed with diabetes every year. This goal would reduce that rate to 40,000 a year by 2020 and prevent 50,000 getting diabetes in this period. Meanwhile, existing efforts on primary prevention will be strengthened with evidence growing about the impact of high levels of sugar in the diet and the World Health Organisation expected to establish new and tougher guidance.

The Diabetes challenge of preventing 50,000 people getting diabetes could save increased costs of 65 million Euros a year after 5 years, or a net present value of 110 million Euros over the five years of the programme. Assuming that the programme is continued thereafter, it would be possible to achieve further savings of 27 million Euro cumulatively each year thereafter. This is a conservative figure based on taking half the estimate in the 2013 Annual Report of the Diabetes Observatory that each person with diabetes costs Euro 1963 each year, increasing at a rate of about 5% a year, but recognising that not all this money can be saved and that the higher costs are likely to be met in later years as the person ages and complications progress.

The Portuguese Diabetes Association (APDP), in association with municipalities and the SNS, will lead local Diabetes coalitions to tackle this problem with the support of health professionals, the Ministry of Health, schools and businesses. It will link with national organisations from other countries to set out and deliver ground breaking plans in this area.

Whilst substantial studies have been undertaken elsewhere, this will be the first time that this level of reduction has been attempted at the level of a whole country. Portugal will be leading the way – and making a significant contribution globally to tackling non-communicable diseases in line with WHO and other policy. This challenge will help demonstrate that cross-sectoral activity of this kind, using evidence from high quality academic studies and with a patients' group in the lead, can achieve important results of long-term national and global significance.

The Children's Challenge

Portugal has a proud record in reducing perinatal mortality to being amongst the lowest in Europe; however, Portuguese children have one of the highest rates of obesity and relatively low levels of well-being. Moreover, a higher proportion of children are living at or near poverty levels in Portugal than in other Western European Countries. All these problems are likely to affect their health in later life and can best be tackled at the earliest stages of a child's life.

This is the longest term of the three *Challenges* and the *Challenge* here is to help the country become a leader in early childhood health and development, with measurable improvements in the health and well-being of children. The Calouste Gulbenkian Foundation proposes to involve all sectors of society – with Education and Health in the lead – in creating plans and taking action to address this goal.

The exact measures to be targeted as signs of improvement and of achieving the *Challenge* will be determined by the participants. Early discussions suggest that these might include an under-5 years developmental measure, a measure on obesity and/or something on educational attainment at school leaving age.

These will be tied in specifically with the UNICEF scale which measures many different factors in determining children's well-being as well as with a proposal for WHO work on social determinants which has a special focus on early childhood development. [5]

Participants in this *Challenge* can learn from and share experiences with other countries that have set out equally bold and important goals for themselves – such as Scotland with its Early Years Collaborative which was described in Chapter 3. This *Challenge* has the potential to demonstrate the progress that can be made by working across sectors and using rigorous improvement methodologies.

The learning environment

The Commission recommended in Chapter 1 the establishment of an expert agency to promote quality improvement, identify and spread good practice and support implementation as part of the essential infrastructure for creating a high quality and sustainable health system for the future. If this proposal is accepted and the agency established, it will be able to take the learning from these three *Challenges* and share it with the whole system thereby helping to establish a truly learning environment in Portugal.

Not only will Portugal be improving the health and well-being of its own population but it will lead the world in doing so. Portugal has the capacity and capability to do so.

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Appendices

1. **The Commission: purpose, methodology and membership**
2. ***"Me and my ideal health system"***
   from Working Group 2's report
3. **Whole of Society Alliance for Health**
   from Working Group 1's report
4. **Transparency**
   from Working Group 2's report
5. **Patient routes for access to information**
   from Working Group 2's report
6. **The evolution of the Portuguese health system**
   from Working Group 1's report
7. **Previous reviews of health financing**

Appendix 1

The Commission: purpose, methodology and membership

PURPOSE

The Calouste Gulbenkian Foundation established the Commission in order "*to create a new vision for health and health care in Portugal, to describe what this would mean in practice and set out how it might be achieved and sustained.*"

The Commission was asked "*to focus on the promotion of health and prevention of disease; the provision of more varied community based and integrated services to meet the needs of the growing number of people with long-term conditions; greater participation of citizens and patients: and the potential impacts of new knowledge and technologies.*"

The Commission focussed on Portugal but it was expected that its work would have global relevance and resonance. Portugal faces many of the same issues as other countries from the growth in non-communicable disease to tough financial constraints and its health outcomes and expenditure are consistent with international norms.

METHODOLOGY

Process

The process adopted by the Commission was considered to be important in establishing a future consensus and in building the motivation for change and the energy and momentum to carry it through the inevitable challenges. The process was designed to be open and engaging, seeking ideas from and consulting with all sectors of the population, and drawing on experience and evidence from around the world.

Whilst the Commission's work built on the successful history of the last 40 years, it ensured that as wide a range of ideas as possible were considered from Portugal and around the world – no matter how radical – that they were submitted to rigorous analysis and tested out with stakeholders.

Although the Chair and 3 of the 6 other members of the Commission were from abroad, the study itself involved a large majority of Portuguese citizens and was firmly based in Portuguese culture. In essence, it was a national study with global implications; facilitated externally but firmly rooted in Portugal.

Structure

The Commission worked through a 4 part structure made up of:

1. The Commission itself which had overall control of the study and approved the final report for presentation to the Calouste Gulbenkian Foundation.

   It concentrated on the big picture – the vision, the social contract, the framework and governance – and on bringing together the insights from the Working Groups into a coherent whole. It was concerned with the practicalities of how to manage change and implementation and identified the key issues which must be addressed and made proposals for action.

   The Commission consisted of a Chair and 6 other members. The 3 Portuguese Commissioners brought insight and experience of the current health system with specialist knowledge of particular aspects or sectors. The Chair and the 3 external Commissioners were able to bring knowledge of other systems and approaches as well as expertise and experience in running big systems and in other areas.

2. Working Groups set up by the Commission to review particular topics and areas and make recommendations to the Commission.

   They were concerned with the more local level of activity, what happened in reality, how particular problems affect the health and access to services of Portuguese people and families, and what innovations and changes could have the most beneficial impact. They were asked to survey their area of responsibility and identify the most promising approaches to be followed.

   Each Group consisted of a Chair and at least 6 others from different backgrounds and at different stages of their careers who are able to bring particular perspective and expertise to the task. They covered:
    1. **Health services and public health**: reviewing service design and delivery, quality improvement and – breaking down existing barriers between organisations, services and sectors where necessary, to meet health needs and support a healthy population
    2. **Citizens and the SNS**: looking at the roles, rights and responsibilities of patients, citizens and others as well as at financial issues, governance and regulation – and seek to create the foundation for a new national consensus and redesign of the existing system
    3. **Staffing the service**: covering human resources, management, professional and non-professional education and training as well as self-care – exploring ways of making the most effective and efficient use of peoples' time, motivations and skills

4. **Harnessing knowledge, technology and innovation**: this will look at academia, industry and health service providers working together to make the best use of knowledge and technology – seeking ways to create a favourable environment for innovation, enhancing competitiveness in health related industries and fostering internationalisation to the benefit of Portuguese patients and citizens

There was some overlap between the topics discussed by the Groups and some common themes such as patient engagement, quality and financing that cut across them all. The Commission reviewed these with the Groups part way through the process and determined how best to handle them.

3. An Advisory Board made up of senior representatives of stakeholders in the health sector which was consulted by the Commission at the outset of the process, for discussion of interim reports and prior to publication of the final report. A second Advisory Group of young professionals was established part way through the process to bring in additional perspectives. The Commission met with them 3 times and established regular contact through emails.

4. A support team working to the Chair of the Commission which was equipped to commission and undertake analysis and to support the logistics of the whole process and promote communications. Part of its role was to ensure that the Commission has access to information on world best practice as well as a clear understanding of what was happening in all parts of Portugal. A second equally important part was project management so as to ensure that the whole process ran smoothly and that communication and consultation was undertaken effectively.

MEMBERSHIP

Commission

Chair – **Lord Nigel Crisp** – Independent Member of the House of Lords and former Chief Executive of the NHS in England and Permanent Secretary of the UK Department of Health.

Donald Berwick – Former Administrator of the Centers for Medicare and Medicaid Services (USA). Former President and CEO of the Institute for Healthcare Improvement.

Ilona Kickbusch – Director of the Global Health Programme at the Graduate Institute of International and Development Studies, Geneva.

Wouter Bos – Chairman of the Board of Directors, VU University Medical Centre. Former Dutch Deputy Prime Minister and Minister of Finances, The Netherlands.

João Lobo Antunes – Chairman of the Department of Neurosurgery at the Lisbon Medical School of University of Lisbon. Founder and President of the Institute of Molecular Medicine, Lisbon Academic Medical Center.

Jorge Soares – Director of Innovation in Health Programme at the Calouste Gulbenkian Foundation. Professor of Pathology at the Faculty of Medicine, University of Lisbon.

Pedro Pita Barros – Professor of Economics and Vice-Rector at Universidade Nova de Lisboa. Research fellow at the Centre for Economic Policy Research in London.

Working groups

1 – **Health Services and Public Health**

José Pereira Miguel (**Chair**) – Professor of Preventive Medicine and Public Health at the Faculty of Medicine, University of Lisbon.

Adalberto Campos Fernandes – Assistant Professor at the National School of Public Health, Universidade Nova de Lisboa. CEO of SAMS Integrated Health Care System.

Manuel Caldas de Almeida – Clinical Director, Hospital Residencial do Mar, Lisbon.

Maria da Conceição Bento – President of Nursing High School, Coimbra.

M. Isabel Loureiro – Professor at the National School of Public Health, Universidade Nova de Lisboa.

Miguel Gouveia – Professor of Economics at the Catolica Lisbon School of Business and Economics.

Paulo Boto – Assistant Professor at the National School of Public Health, Universidade Nova de Lisboa.

Raul Mascarenhas – Vice-President, WeDo Technologies.

Rui Portugal – Executive Director of the National Health Plan, Directorate-General for Health, Ministry of Health.

Víctor Ramos – GP, Professor at the National School of Public Health, Universidade Nova de Lisboa.

2 – **Citizens and the SNS**

José Carlos Lopes Martins (**Chair**) – Director and member of the Board of José de Mello Saúde Private Hospitals.
José Manuel Boavida – Director of National Diabetes Programme, Directorate-General for Health, Ministry of Health.
Lynne Archibald – President of Laço (Patients Association for Breast Cancer Prevention and Early Diagnosis).
Paula Martinho da Silva – Former chairperson of the National Committee of Ethics for Life Sciences.
Vítor Neves – President of Europacolon (Colorectal Cancer Patients Association).
Luís Campos – President of the National Council for Quality in Healthcare.
Isa Alves – Head of Marketing and Communication at the Institute of Hygiene and Tropical Medicine, Universidade Nova de Lisboa.

3 – **Staffing the Service**

Maria do Céu Machado (**Chair**) – Head of the Department of Paediatrics, Hospital de Santa Maria and Professor of Paediatrics at the Faculty of Medicine, University of Lisbon.
Carlota Vieira – Directorate-General for Health, Ministry of Health.
Casimiro Dias – World Health Organization staff member at Copenhagen.
Ema Paulino – President of Lisbon and South Branch of the Portuguese Pharmaceutical Society. Member of the Executive Committee of the International Pharmaceutical Federation.
Manuel Areias Sobrinho Simões – Professor of Hematology at the Faculty of Medicine, University of Porto.
Maria Augusta Sousa – Former chair of the Portuguese Nurses National Association.
Marta Temido – President of Portuguese Association of Hospital Administrators. Member of the board of the Cantanhede Hospital. Professor at the Faculty of Pharmacy, Coimbra University.
Ponciano Oliveira – Deputy Chairman at the board of North Regional Health Authority, Ministry of Health.

4 – **Harnessing knowledge, technology and innovation**

Peter Villax (**Chair**) **–** Vice-President of Hovione Comp., Health Cluster Portugal Board Director.

António Portela – CEO of Bial Pharmaceutical Comp.
Carlos Faro – Biocant Ventures, Portugal.
Daniel Bessa – Director of COTEC – Association for Entrepreneurship and Innovation.
Joaquim Cunha – Executive Director of Health Cluster Portugal.
Manuel Heitor – Professor at the School of Engineering, Science and Technology at the University of Lisbon. Former Secretary of State for Science.
Maria João Queiroz – Director of Eurotrials.
Nuno Sousa – Professor at Health Sciences School, University of Minho.
Pedro Noronha Pissarra – Chairman and Chief Executive Officer of Biotecnol SA.

Advisory Board

Luís Portela (Chair) – Chairman of Bial Pharmaceutical Company, President of the General Council of the University of Porto and President of the Health Cluster Portugal.
Isabel Vaz – CEO of Espírito Santo Saúde.
Manuel Rodrigues Gomes – Professor Emeritus of Cardiothoracic Surgery at the Faculty of Medicine, University of Porto.
Manuel Sobrinho Simões – Chairman of the Institute of Molecular Pathology and Immunology of the University of Porto, Professor of Pathology at the Faculty of Medicine, University of Porto.
António Coutinho – Chairman of the Portuguese National Council for Science and Technology and Professor of Immunology at the Faculty of Medicine, University of Lisbon.
Jorge Simões – President of the Portuguese Health Regulation Authority, Professor of the Health Sciences Department, University of Aveiro.

Young professionals group

Ana Carlota Dias
Ana Costa
Cláudia Reis
Daniel Simões
Diogo Medina
Gonçalo Martins
João de Almeida Pedro
Liliana Laranjo
Mara de Sousa Freitas
Ricardo Fernandes
Ricardo Mexia
Rute Borrego
Sandra Duque Maurício

Support team

Sérgio Gulbenkian (Project Leader) – Deputy Director at the Calouste Gulbenkian Foundation (Innovation in Health Programme). Auxiliary Professor of Pathology at the Faculty of Medicine, University of Lisbon.
Lucy Irvine – Researcher and Health Policy Analyst.
Francisco Cluny Rodrigues – Health Economy Analyst.
Francisco Wemans – Health Economy Analyst.
Inês Pinto Mascarenhas – Administrative Manager, Calouste Gulbenkian Foundation.

Appendix 2
"Me and my ideal health system"

WORKING GROUP 2

In my ideal health system, I am healthy from my safe and peaceful birth to my dignified death, late in life, surrounded by my family. I have very little reason to interact directly with the system itself physically, apart from preventive measures, like vaccines or screening, and rare acute situations like unavoidable illness or accidents. When I have to go to a Wellness Centre for proactive health care or a hospital for urgent treatment or serious medical issues, my problem is solved professionally and with humanity at that location, in as little time as possible.

My parents have the knowledge and resources to feed me in a healthy way and I have access to safe playgrounds and outdoor recreation facilities. Safety is a priority at my school and general legal requirements help keep me safe and healthy – like fences around pools, mandatory child car seats, helmets for sports and no smoking in public places. When I go to school, the lunchroom serves healthy meals and junk food is not a part of my life. My school has a psychologist who watches out for children at risk and coordinates with the school and when needed social services and my health manager, and the police in extreme cases. The curriculum of all grades, from 1 through 12, includes health modules every term and most schools have guest speakers from recognized NGOs speak on different topics. The physical education programme includes regular team sports but also focuses on individual activity goals. My parents regularly take me to see my health manager annually (a pediatric specialist until I am 18) and my health manager communicates with the health manager of my parents if needed. I have had all the vaccines currently available. My parents get texts reminding them when to take me in. I have an online health record that my parents can access and I can too once I'm old enough. They get emails about information related specifically to me and my age/gender group and I get information directly via cell phone for my age/gender and any specific health interests that I have. When they have doubts, they can look up most information online, as can I.

As an adult, I continue to get helpful reminders and new information via SMS and my online record is passed to my new adult health manager. At work, I get an annual bonus for not needing to use my sick days. I bike to work unless the weather is bad. My company has yoga classes before and after work and the neighbourhood has lots of restaurants that sell fresh healthy lunch food. Like all eating establishments, nutritional information is available about each choice on the menu.

When I have a specific question about my health, I text the cell phone of my health manager (or send an email in case of something needing a longer explanation) and they get back to me that day. They might ask me to send more diagnostic information from my cell phone. Then they either give me an answer that solves my problem or they schedule an appointment with them or the person best able to resolve my issue within the next week.

In the case of an appointment, I arrive on time at the government funded and run Wellness Centre which has parking, public transport access and is wheelchair accessible. This facility, which is in my community, resolves all my ambulatory issues: vaccines, screening procedures, prenatal care and diagnostic exams including imaging exams. The Wellness Centre employs a range of health care professionals including nurses, nurse practitioners, midwives, optometrists, psychologists, nutritionists, laboratory technicians, dentists, ophthalmologists, pediatricians, gynecologists, family practice doctors and internists. They treat me with respect and sensitivity. They all smile a lot. One of the reasons they smile a lot is that they are well paid and highly respected. The Centre serves just enough patients to make it financially viable but no more, so that personal relationships can develop. The Centre is not at all luxurious but has the resources to guarantee that patients are well treated. Getting a job at a Wellness Centre is very competitive because of the high pay, the great working atmosphere and the ongoing relationships with patients.

I am on the Board of this facility as a volunteer lay representative. The Board meets once a quarter and decides matters relating to local issues, staffing and budget allocation. I also volunteer there once a month in the Seniors Programme which puts volunteers in touch with elderly users of the centre who have mobility issues. This Programme is run in conjunction with a national NGO. The Centre opens early 2 mornings a week and stays open late 2 nights a week to encourage working adults to use the preventive services and family planning services in particular. Teens over the age of 12 can come alone if preferred.

EMERGENCY

In the case of an emergency, I contact my health manager by cell phone to let them know what is happening and where I am going for emergency help. When I arrive at the hospital, the hospital has access to my health records and my health manager. I might have to wait as life threatening situations are always given priority. If my problem can be resolved at that time (stitches, cast), I'll expect to be discharged that day and to have a follow up care appointment already booked with my health manager back at my Wellness Centre. If I need emergency surgery, I would expect to be admitted.

CHRONIC DISEASE/SERIOUS ILLNESS

Given my mother's healthy habits while pregnant with me and my healthy lifestyle from an early age, I hope to never get a chronic disease or a serious illness. If I do, I would like to be an active partner in my care and to do as much as possible on an outpatient basis and to perform the bulk of my care via self-management. My health manager would need to be an expert in my condition and so though I would remain connected to my primary Wellness Centre, most of my interaction would be with and via my new chronic/serious disease coordinator.

Like the one stop "Lost your Wallet" service at the *Loja do Cidadão*, no one wants to need health care but I really appreciate what a great service it is if and when I do need it! Overall the health care system functions in the background of my life and I only access it when I really need to and then the experience is pleasant and efficient.

Lynne Archibald, 2013

Appendix 3
Whole of Society Alliance for Health

WORKING GROUP 1

BETTER GOVERNANCE FOR HEALTH THROUGH A WHOLE OF SOCIETY ALLIANCE FOR HEALTH

The WG proposes the creation of a structure to promote better Governance for Health – a Whole of Society Alliance for Health (WOSAH). It should take into account all the issues listed below and create synergies from what already exists in the different and most relevant sectors of society, and draw on evidence of best practice in Portugal and internationally.

NATURE AND MISSION

- WOSAH is an independent, consultative and scientific advocacy body that works with the Parliament and the Government. Its work will be developed with technical and scientific autonomy and assuring accountability.
- The mission of WOSAH is to promote knowledge dissemination and co-responsibility of other sectors and stakeholders for public health improvement. A strategy of coordination should be put in place with the different sectors and stakeholders.
- WOSAH supports the definition and implementation of health policies and strategies at national and local levels through participatory process. It works in liaison with the existing public health services stimulating inter-sectorial work for health.
- The Alliance provides coordination for establishing health strategies and for planning, implementation and evaluation. It contributes to the definition of priority areas and programmes by promoting interdepartmental coordination, particularly among health system, social protection, education, environment and transportation sectors.
- The Alliance advices in health policy planning, implementation and health impact assessment. It contributes to the definition of priority areas by promoting interdepartmental coordination of policies, particularly among health, social protection and education sectors.

- WoSAH acts at specific request of the Parliament or Government, by its own initiative or at request of other entities such as municipalities, public health organizations, NGOs.

RESPONSIBILITIES

WoSAH advocates and promotes a whole of government and whole of society involvement in the improvement of health and well-being. It will foster organizational quality in all sectors, eg. services network, social networks, educational networks and others.

Coordination at regional and local levels, assured by organisations already in place, promoting a bottom-up approach, supporting citizens participation and representativeness.

- Through a participatory diagnosis and definition of strategies at local and intermediate levels, WoSAH contributes to identify priority areas in health for the intervention of the different sectors. This will result in a Strategic Plan that must take into account sectorial plans, namely the National Health Plan.
- WoSAH promotes dissemination of research and scientific production and policy in the field of public health.
- To increase knowledge and translation of successful practices in health promotion, including policy design and implementation applied to concrete interventions;
- Translation to new settings of successful experiences, for instance, from healthy cities, health promoting schools, health promoting hospitals, and health promoting workplaces.
- Urban planning to achieve friendly cities for children and elderly and so, friendly cities for all.
- Action research on policies, models of implementation and practices for local social development and social inclusion.

COMPOSITION AND MANDATE

A public health is composed by a set of experts organized in multidisciplinary committees by areas of knowledge action. The Board of the Alliance is chosen by the Parliament, for a five year mandate. Furthermore, members will be chosen from the following sectors and areas: health, environment, education, social welfare and transportation. The WoSAH may require consultancy by universities, NGO, research centres, health professionals. To prepare the Alliance's implementation phase, similar bodies – whether national or international – will be consulted.

KEY STRATEGIC AREAS

1. Introduction of legislation that establishes as mandatory certain political decisions to be adjusted through HIA methodologies.
2. Establishing a monitoring policy with explicit focus on issues of the use of HIA and implementation of HiAP.
3. Advocacy for HiAP and public health activism, using the actual context of social and economic crisis as an opportunity for taking effective decisions and put into practice integrated projects in key sectors and levels of intervention.
4. To develop Equity focused Health Impact Assessment (EfHIA).
5. Correlate the adequate alignment of opportunities with strategic investment in health plans and programs.
6. The Government has announced a change in pension rules defining the legal pensionable age. It might be feasible as part of these ongoing changes that in a short time legislative action includes and facilitates the possibility of partial retirement based on actuarial calculations to ensure this becomes a win–win policy for retirees and taxpayers.
7. Integrate in the National Health Plan strong strategies and tools for governance and effective involvement of other sectors.

CAPACITY BUILDING AND HEALTH LITERACY

WoSAH should support multi-professional postgraduate training spaces, where students learn together to work and make decisions in multidisciplinary teams. Ideally, this should arise from the integration of common course units and modules in the curricula of the different courses (medicine, nursing, public health, nutrition, etc.), to be jointly attended, and where students are challenged to solve problems, as a team, by looking at them through the perspective of the different professional areas.

It will also support the introduction and reinforcement of health literacy-related content in health professionals' curricula (including medical doctors, nurses, psychologists, nutritionists, technicians and other allied health professionals).

Finally, it will recommend reinforcement of the Health Research Agenda to support and national strategies for public health (including health promotion, health protection and disease prevention) to meet the major health challenges, nationally and within the EU. Public health research, including in the area of health services research, should be guaranteed sufficient funding and resources – a minimum of 25% of all health research funding should be allocated to public health, as it contributes to the economic development of the country.

Appendix 4

Transparency

Working Group 2

TRANSPARENCY

Conflict of interest, the clash between an individual's self-interest and the public interest, is a problem in all health systems. The goal of transparency is to bring conflicts of interest out into the open so that all stakeholders have the same information leading to fairness and the furthering of the public good.

Quality, accountability and transparency are interdependent. Major steps forward have been taken recently in Portugal but more needs to be done, both for citizens and by citizens and it doesn't only hinge on the sharing of information: "Simply making information available is not sufficient to achieve transparency. Large amounts of raw information in the public domain may breed opacity rather than transparency."

The following are proposals for improvements to transparency in Portugal in seven priority areas from the point of view of citizens:

1) Conflicts of interest

Health professionals in Portugal are ethically bound to put their patients' health first but several areas of conflict of interest need to be improved:

- The concept of conflict of interest needs to be openly discussed in the public domain. There is a *Conselho de Prevenção de Corrupção* (CPC) which has recommended that public entities develop and disseminate formal plans for preventing corruption in public institutions. However the CPC is almost unknown and although the list of entities already complied includes numerous health organizations (such as IPO, Hospital Sta Maria) it is very difficult to find the policies themselves. Exceptions include the *ARS de Lisboa e Vale do Tejo* which has their policy on their site as does the *Unidade Local de Saúde de Matosinhos*.
- All health institutions (private and public) need to have simple, widely disseminated "Conflict of Interest" policies which clearly prohibit situations of conflict of interest or potential conflict of interest (including relationships with pharmaceutical companies, medical devices makers, outside laboratories, academic entities, government bodies, regulatory agencies and other health service providers).

- Conflict of interest also happens frequently in the accumulation of positions, both within the public and private sectors of healthcare and during and after government service. Increasing the number of lay people on decision-making boards could help. All members of decision-making boards should be required to publish full disclosure statements, clearly indicating financial interests including employment and consulting work.
- Historical low remuneration in the public system led to a situation in which most health professionals in the public system had to also work in the private system at the same time. This historical overlap between the public and private sectors has led to institutionalised conflict of interest. The practice by individual doctors of referring citizens in a public hospital to their own private clinics still continues. But it is also common practice for citizens to "jump the queue" by first consulting a doctor at his or her private office when they want an operation at a public hospital. ERS has begun to investigate, sanction and publicize these situations but as taxpayers and patients, citizens need to be more active whistle blowers. Proper remuneration in the public system could decrease the need for professionals to work in different places and exclusivity to one system or the other could increase efficiency and minimise conflicts of interest.

2) Transparency and the influence of the pharmaceutical industry and medical device makers

On February 14th, 2013, a new law came into effect in Portugal which makes it compulsory for all pharmaceutical companies to declare their support to health professionals, health non- profits and public health entities. The list of donations and sponsorship is made public on the site of Infarmed. However, it is very difficult to find the list without the direct link. Although the site has been improved since its launch (the alphabetical list can be searched by donor or recipient and by size of donation), it remains slow and shows a very limited amount of information per screen. To search for a particular company or recipient takes hours. The site needs to be greatly improved in order to make any real difference to transparency. The site should also encompass medical device makers.

Citizens need to use the information that is available to fight for accountability. After initial reports in the media about the new law, only one follow up article was found.

3) Transparency of information about the quality of health service providers in Portugal

Information paid for by the public always needs to be made public in ways that are comprehensible and useful. ERS has started to roll out the SINAS system but at the moment it is difficult to use it for concrete decisions about where patients will be best cared for. Citizens need clear information with various levels of detail to help them understand their choices and make the best decisions in general and more specific health situations. There is an urgent need for one coherent health site that brings together links to this and many other kinds of information. The rule should be that information is automatically disclosed, and should only be withheld for legitimate legal exceptions. At present, there are a large number of these qualifiers, meaning that it is easy for access to information to be denied, and a next step might be to hold a public consultation on these in order to more narrowly define them.

Private health entities should also be concerned about publicizing their health outcome results because it is a driver for improvement and increasingly will become a marketing tool. The role of the media is key in bringing this information to the public in a responsible way. There is a Freedom of Information law known as LADA (Lei do Acesso aos Documentos Administrativos) which guarantees access to government documents. However there are a large number of exceptions to the law which are often invoked by entities to avoid revealing information. It is possible to appeal to CADA (Comissão de Acesso aos Documentos Administrativos) but the process is complicated and highly bureaucratic and little used by journalists. Recent cases brought before CADA in the area of health include several individuals trying to get access to their own health records.

As previously discussed, the multiple complaint processes need to be streamlined into one entity and made much more transparent. The *Ordem dos Médicos* currently receives complaints about specific doctors through their “Patient Office”. However, the public is not informed about the cases which are sent for Disciplinary Review. The inherent conflict of interest here leads many patients to feel that the goal of the office is to protect doctors. As previously suggested, an independent Patients’ Ombudsman, possibly working with ERS, could play a significant part in helping patients and citizens feel that their best interests are being looked out for.

4) The lack of transparency in the area of health non-profits

Once an association is officially designated as a charitable entity (IPSS), there is no meaningful further supervision. Those that receive government funds are supposed to submit final accounts and an annual report every spring and then a budget and plan for the coming year every autumn. The forms are inadequate for many entities and there is no enforcement. Associations that do not receive government funds are no longer required to submit anything. There is no control or transparency in terms of governance and conflict of interest. The public does not have enough information to make decisions about whether or not a non-profit deserves their support.

There is a history of non-profits serving as 3rd party sub-contractors to the public health system by providing urgently needed health related support services in areas that the public system cannot/does not cover adequately (for example, services for disabled children and adults) in return for government funding.

While the new disclosure rules should bring to light some of the unclear relationships between many associations, professional groups and the pharmaceutical industry, the INFARMED site will need to be enhanced to make a difference.

Although certain key foundations have had a profoundly positive impact on health care in Portugal, it is common for foundations to be completely opaque about their funding. Patients with serious illnesses are particularly vulnerable to initiatives that may not always be upfront about their objectives – for example, websites that encourage patients to share their experiences with medications and side effects but do not acknowledge that the sites are funded and run by drug companies or that the sites sell the information to drug companies.

5) Academic transparency

National medical academic requirements simply ask authors to self-report any conflict of interest and whether they had outside funding. Given that the perception of conflict of interest tends to be extremely low in Portugal, it is not surprising that self-reporting is equally low. National academic transparency would be enhanced by adopting more rigorous requirements for disclosure.

While there are not many clinical trials in Portugal, it is difficult to find information about these trials on any level (participation, transparency, results). In March 2012, INFARMED launched a new portal that is designed to be a clearing house for this information. Unfortunately, the site is not designed for use by citizens or patient groups.

6) Transparency of the safety of confidential patient health records

With the advent of vast electronic medical databases, patients need to know that their personal information will be protected at all times. This is not always the case.

The ownership of patient records needs to be determined in a clear and transparent way, both in the public and private health systems. There should be formalized processes in each institution, to allow patients access to their own clinical information, safely, quickly and simply. The patient has the right to access information that concerns them at any time they wish and in a form understandable to them. This information should include data on the pathology, diagnosis, medical procedures, tests, treatments, evolution, identification of the technicians involved in the treatment, etc.

7) Price transparency

As the private sector develops in Portugal, price transparency in the private healthcare sector should increase to allow potential patients to use price as a factor in their health choices. Instances have been reported in which patients were not fully informed of the cost of their treatment options.

In the public sector, several ideas have been floated about giving patients information about the costs of the “free” healthcare that they are receiving. Even ballpark figures would increase citizens’ understanding of the costs of public healthcare and could bring more perspective to the question of user fees.

Appendix 5

Patient routes for access to information

WORKING GROUP 2

To create reference tools for access to health information by the citizen:

a. **Health website**
   The development of a portal which gathers and organizes all the useful information from the healthcare sector, not only information in the area of health promotion, disease prevention and health services (similar to a portal such as Fiocruz, Brazil[1]), but also indicators and information on the quality of service, promoting a culture of transparency and accountability.

b. **Health store**
   Following the philosophy of Citizen Shop, Health Shop would be a space which citizens can visit physically to get information about health services in Portugal, whether public or private, as well as information on laws, responsibilities and rights. They would also be able to have access to several informative materials, also available on the Health website. Providing a public information post will become particularly important role for the population without access to the Internet (e.g.: the elderly).

c. **Telephone helpline**
   It would work like the "Saúde 24" line, but it would provide other information to help citizens to orient themselves within the Portuguese health system and to know their rights and duties, namely in what situations will have to pay user fees, etc.

d. **Health channel**
   To create a channel dedicated to health promotion and disease prevention, with the goal of increasing information and health literacy of citizens, contractually between the Ministry of Health and the providers of cable television and made available online through the Portal of Health.

To create a network of partners / stakeholders

Health institutions should seek to join forces and establish partnerships with stakeholders (e.g. patient organizations, aid groups, local authorities, voluntary organizations, religious groups, foundations) for the development of its agenda for health information.

To improve the access to clinical individual information of patients.

To implement an electronic health database, taking into account the confidentiality of information and having an e-health framework strategy.

References

[1] http://portal.fiocruz.br/pt-br/content/ communicates% C3% A7% C3% A30-and-reports% C3% A7% C3% A30

Appendix 6
The evolution of the Portuguese health system

Working Group 1

LANDMARKS IN THE PORTUGUESE HEALTH SYSTEM EVOLUTION

The evolution of the Portuguese health care system, including its public health services, has been fairly consistent over the last 50 years, aside from some short periods of instability.

The prospective long-term vision of what would be a suitable health care system for Portugal has its roots in the 1960's and 1970's. This was possible through the leadership of highly competent and visionary persons, most of them open minded medical doctors. Almost all of them opposed firmly the political regimen that ended in 1974. The democratization of Portugal in the years that followed the revolution of 1974 and the international conference of WHO/UNICEF on primary health care in 1978, brought the opportunity and the inspiration to expand and to consolidate the ideas and perspectives of those pioneers.

The most remarkable achievement of all those dreams and efforts was the implementation of the SNS and its outcomes for the well-being of the population in terms of health gains. However, in its first 33 years, the SNS still does not have a formal recognized identity or a specific common corporate culture. It also does not have a clearly unified strategic governance system. It has been surviving under a pendulous movement between initiatives aiming at the reinforcement of a status of a public mission organization with a well-established trade mark and, in other periods, initiatives to move into a combination of a diversity of organizations and stakeholders with different cultures and aims, with the reinforcement of the involvement of private for-profit entities and organizations.

The main phases and landmarks of the evolution of the Portuguese health care system, during the period 1960-2013, are summarised in the table 1.

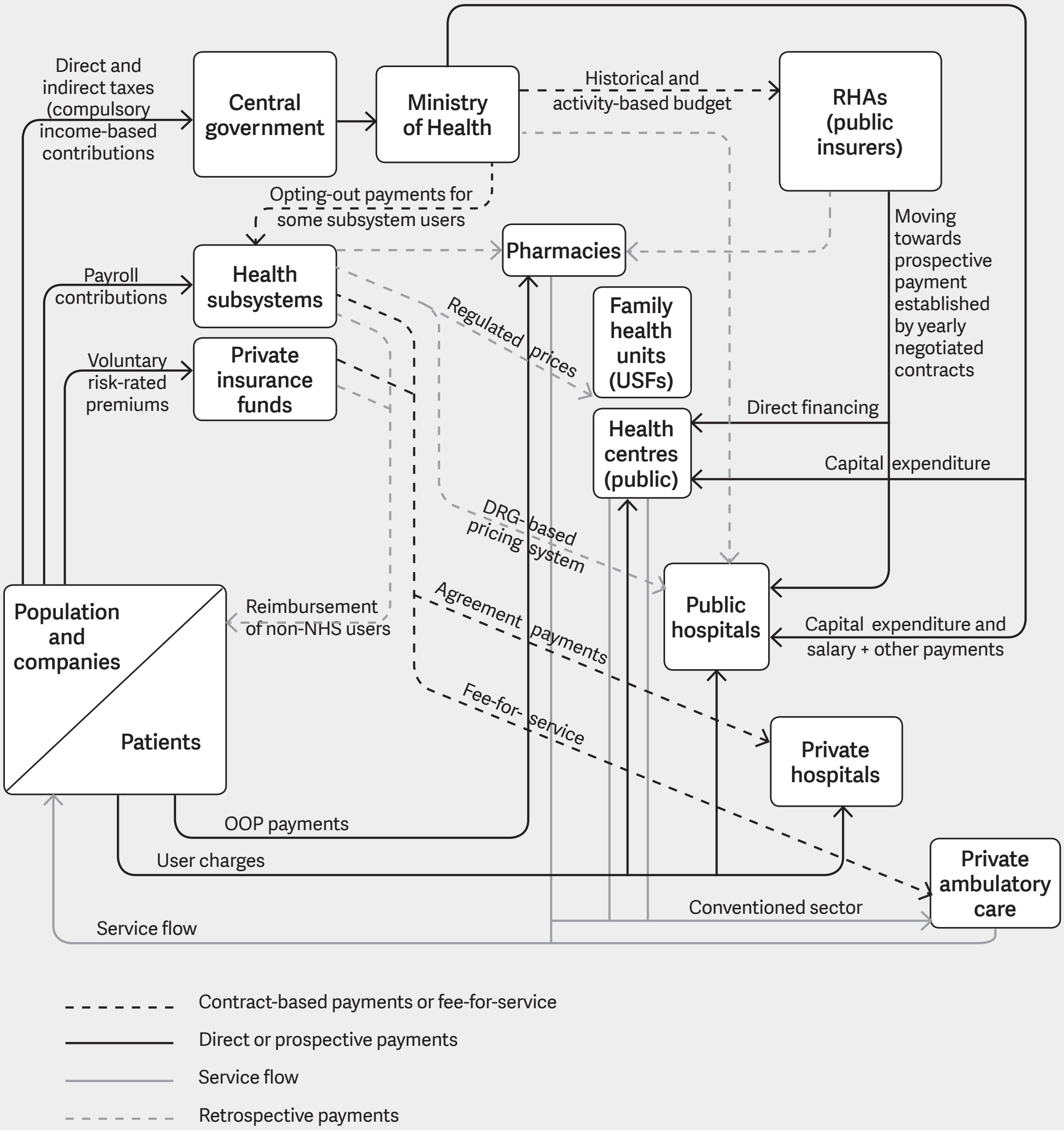
Table I · **Evolution of the architecture of the Portuguese Health Care System 1960-2013**

Period	Main emphasis	Landmarks and main issues
1961 – 1971	Special emphasis in PH	• Historical report of the Portuguese "Ordem dos Médicos" on the medical careers (1961) • Launching of great PH interventions (1965) – for example the national vaccination plan. • Launching of a nationwide network of community health centres with the main objectives of health promotion, PH protection and disease prevention – 7 years before the International Conference for Primary Health Care, promoted by WHO and UNICEF in 1978 – (Decree-law 413/1971) • Legal establishment and regulation of two medical careers (hospital medical career and PH medical career) in line with an integrated health care vision (Decree-law 414/1971)
1971 – 1981	Special emphasis in organizing health care	• Building / installing around 300 primary care health centres all over the country (1971-1973) • Building / installing around 20 new district hospitals under the responsibility of the State (until then, 90% of the hospitals were mercy's owned by the Misericórdias (1971-1981) • Revolution of April 1974 • Five years of debates that led to the establishment of the SNS (1974-1979) • Implementation of a transitory "medical service in periphery areas" (SMP - "Serviço Médico à Periferia") from 1975 to 1981 – provided by young medical doctors as a condition to join the future SNS – one year of "civic" medical service in deprived areas with a shortage of doctors • Beginning of the SNS (Law of September 1979) • First attempts to define the new medical career of general practice / family medicine (first legal "draft" in 1977; the Horder Report (1979); second legal "draft" in 1979; first vocational training programme (residency) for the new "generalist" (general practice/family medicine) – a new medical specialty (1981)
1981 – 1985	SNS identity and its common "corporate culture"	• Publication of the first numbers of the "SNS Newsletter" and the first and ephemeral "logo" of the Portuguese SNS, under the leadership of the Secretary of State for Health Dr. Paulo Mendo (1982) • Beginning of a new medical career of general practice (1982-1985) with the distribution in 3 years of around 5000 young doctors all over the country – around 90% started as basic doctors who should accomplish an in-service GP training programme to became specialists in GP/family medicine; 10% followed, since the beginning, a structured vocational / residency training programme, 3 years long, to became specialists in GP / family medicine, who trained the others • There were raised resistances to the establishment of a unified and coherent governance for the SNS. These resistances came from many sources, specially from the 12 vertical central services (general-directorates) of the MoH. The rapid changes of governments and the economic and social difficulties at that time damaged the "systemic memory" and the maintenance of the SNS leadership in line with its foundation roots principles

Period	**Main emphasis**	**Landmarks and main issues**
1985 – 1995	Market mechanisms and the health system	• New law for the entire health system (Lei de Bases da Saúde – 1990) • New law for the SNS, with five regional health administrations without a unified strategic governance • Maintenance of the separate and diverse general-directorates of the MoH • Attempt to initiate a social health insurance in a “opting out” scheme from the SNS (failed) • Attempts to initiate private management of SNS public hospitals and to privatize public services of the SNS
1995 - 2000	Return to the foundational principles of the SNS	• Efforts to strength PH and public responsibilities with health, starting with accountability concerns and new approaches to manage the change in complex social systems and to deal with organizational and professional human motivations: - Beginning the strategic planning for health (1997/1998) - Attempt to re-organize SNS hospitals into networks of autonomous but interdependent clinical centres with explicit mechanisms for accountability (only one experience was put into practice) - Beginning of the re-organization of PHC health centres into networks of small multiprofessional teams with responsibility for a defined practice population (19 experiences – a rapid expansion phase would take place after 2006) - Introduction of the “local health system” concept with community co-responsibility and participation (a law was passed, but few experiences started); - Beginning of the concept and procedures of commissioning and contracting health care within the SNS (still exists with some developments) - Re-organization of the PH services
2000 – 2005	Return to the privatization trend	• Return to the privatization trend, with explicit resistance to the building of a specific SNS identity and a SNS unified corporate governance - Transforming several SPA hospitals into SA Hospitals - Attempt to follow the same trend in PHC - Creation of a specific regulation entity (Entidade Reguladora da Saúde) by imposition of the President of the Republic as a condition to accept the precedent initiatives
2005 – 2013	Return to the foundational principles of the SNS “Bottom up” organizational changes in PHC	• SA Hospitals became EPE Hospitals (public entreprises) • In PHC a team-work bottom–up approach was energically adopted (“*let the innovators fly and protect them from the hunters*”); • Attempts to transform the front-line PHC provider hierarchies into networks of small autonomous, accountable and regulated multiprofessional teams (*permanent structural teams*); • Move management functions closer to the teams of providers (*“stewardship” functions instead of command-control habits*); • Introduction of the concept and practices of “health and clinical governance” at primary care level (*interacting also with hospitals, long term care and community partners*); • Strengthening the participation and co-responsibility of citizens and of communities in PHC (*citizens cabinets and community councils for health, these with the possibility to get executive power in primary health care management* – in implementation phase

As a consequence of this evolution, the Portuguese Health System is characterized by three coexisting and overlapping systems (the SNS, health subsystems and private insurance funds) as shown in the figure 1 below.

Figure 1 · **Overview chart of the health system (adapted from Barros, Machado, Simões, 2011)**



Appendix 7

Previous reviews of health financing

There have been six reviews of health financing carried out over the last 22 years. Table 1 provides a summary of the proposals of these reviews in five key areas. It shows that:

- In column 1: there has been a mixed view on user fees. User fees were doubled as part of the implementation of the Memorandum of Understanding in 2012
- In column 2: recent reviews were opposed to the ability to opt out of the NHS after experience of this between 1997 and 2005
- In column 3: 4 of the 5 recent reviews were in favour of keeping tax as the main basis for funding, the only difference with the CRES review in 1998 was that it favoured a hypothecated tax rather than funding from general taxation
- In column 4: 5 out of 6 favoured some limits to the treatments covered by the SNS. The Gulbenkian Commission proposes in Chapter 4 that this should be done through a new agency, SNS Evidence, which would base its advice on assessment of what were the most effective treatments
- In column 5: 5 out of 6 favour health funding being kept separate from social security funding; whilst the exception – the APES review of 1996 – wanted linked funding

Table 1 · **Summary of proposals from previous reviews of health financing**

	Increase in out-of-pocket payments	Opting-out	Taxes	Coverage limits	Social insurance
Mendo *et al.* (1992)	Yes	Yes	No (?)	Yes	No
Lucena, Gouveia e Barros (1995)	No	Yes	Yes	Yes	No
APES (1996)	No	No (?)	Yes	No	No
CRES (1998)	No	No	No	Yes	Yes
Simões *et al.* (2008)	Yes	No	Yes	Yes	No
MoU (2011)	Yes	No	Yes	Yes	No

Source: adapted from Simões *et al.* (2008), Table 4, page 67