A report by the All Party Parliamentary Groups on Global Health; HIV/AIDs; Population, Development and Reproductive Health; Global Tuberculosis; and Patient and Public Involvement in Health and Social Care

Patient empowerment: for better quality, more sustainable health services globally

Report

Abbreviations

APPG	All Party Parliamentary Group
ART	Anti-Retroviral Therapy
DFID	Department for International Development
EPP	Expert Patients Programme
GP	General Practitioner
MI	Motivational Interviewing
MP	Member of Parliament
NHS	National Health Service
PDA	Patient Decision Aid
RMC	Respectful Maternity Care
SDM	Shared Decision Making
TASO	The AIDS Support Organisation
UN	United Nations
WHO	World Health Organization

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Preface

This report takes a global perspective on an issue that concerns us all, wherever we live: whether healthcare is something that is done 'to' us or 'with' us.

Ill health can be profoundly disempowering, but we should all have the chance to understand what is wrong, be involved in making decisions about our treatment, and take responsibility for managing the parts of our care that we are able to. Providing care in this way isn't just a vital component of good quality, it's also essential to the sustainability of health systems for the future. This is as true for the UK as it is for countries where many people never see a doctor during their lifetime.

The NHS has made real progress over the years in strengthening the patient role. Thanks to huge social and technological change, reforms to professional education, the commitment of successive governments and many other factors, the role of the patient is slowly becoming less passive. Still, examples of poor care are not hard to find and in several key areas we have struggled to see any improvement for over a decade.

As six All Party Parliamentary Groups working together, we wanted to look at the global picture on patient empowerment. As this report outlines, we found there is a great deal the UK can learn from other countries about transforming systems, behaviours and mindsets to change the patient role. At the same time, there are also things other countries can learn from the UK, and the report suggests a number of practical ways the UK could be doing more to support the empowerment of patients abroad.

Underlying the whole report is the simple message that giving renewed emphasis and investment to patient empowerment at every level will help improve quality and make health systems more sustainable.

We would like to thank all those who contributed examples, ideas and evidence to make this review possible. In particular, we would like to thank the review's research lead Jonty Roland and the team of coordinators, advisors and interns that supported our APPGs, which included Vanessa Halipi, Susie Grady, Lucy Fagan, Callum Totten, Mette Kjaeby, Matthew Oliver, Teddy Hla, Isaac Ghinai, Catherine Rushworth and William Burch.

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Executive Summary

Healthcare systems around the world are becoming increasingly interested in strengthening the role of patients in their own care. In the UK, patient empowerment has been an objective of successive governments over many years, with recent initiatives including new networks of local patient groups and support for greater self-management of chronic conditions. For the most part, however, the effects of these changes have been disappointing, with national policies continuing to emphasise the need for fundamental change.

Other countries – including low and middle income nations – are also grappling with the need to move away from traditional notions of the patient as passive recipient. With pressures of non-communicable disease, ageing and a critical shortage of health workers globally, new models of care are emerging with greater patient rights and responsibilities at their foundation.

This report highlights some of the lessons and examples from this increasingly global patient empowerment movement. The primary focus is on the role of individuals in their own healthcare, although overlap with the equally important issues of public involvement in health and empowerment in social care are recognised.

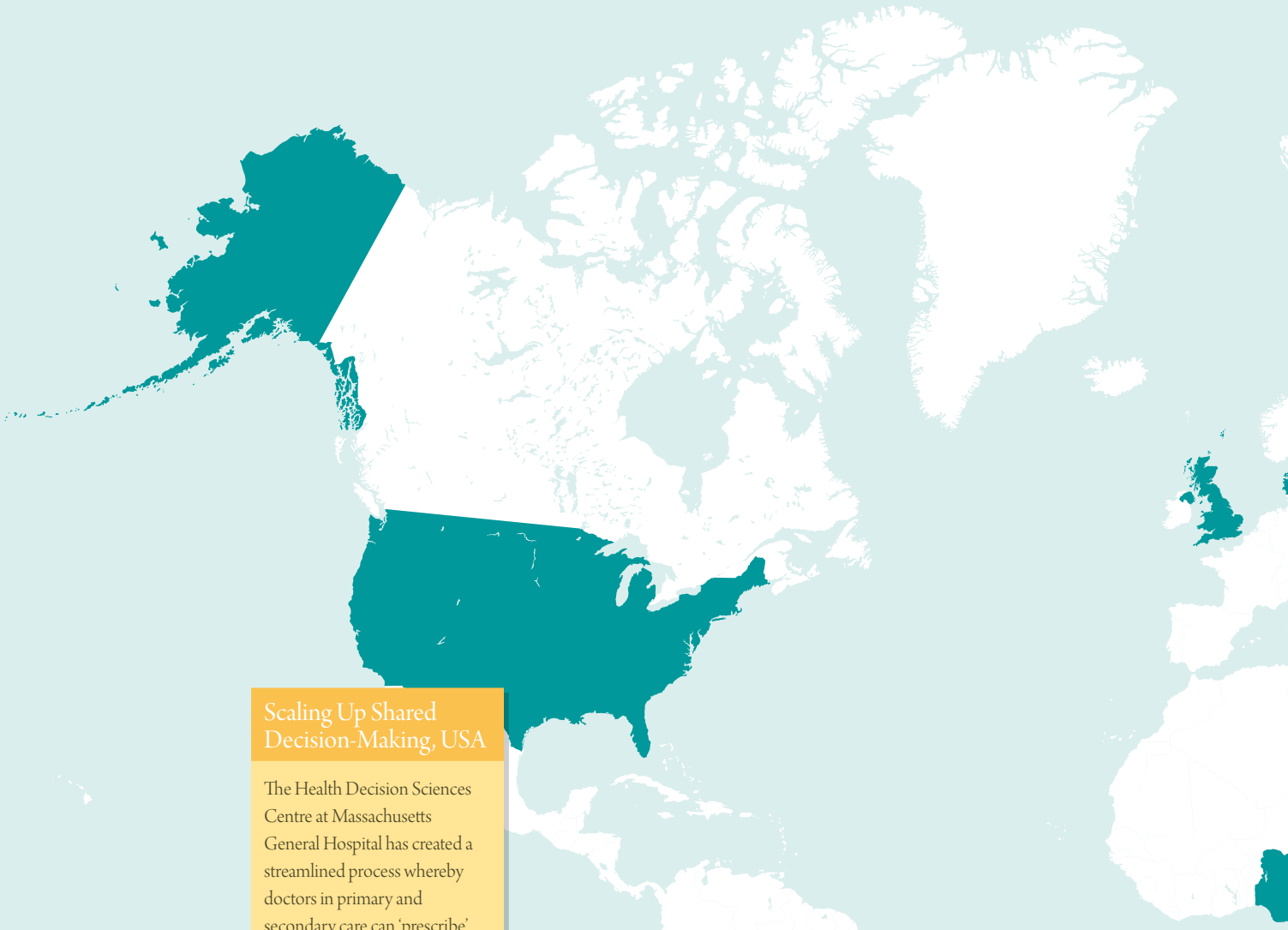
Part I: Global lessons

Across over 100 overseas examples of patient empowerment submitted to this review, a clear message emerged: that by giving patients the opportunity to expand their role – and equipping them to do so - fundamentally new models of care are possible. These new kinds of services aren't just more efficient, they also bring healthcare back to its core values of dignity, safety and respect.

> *"One of the striking opportunities in some of the developing health systems is that they're starting from a different place where they need to use all the assets available beyond the health system– we haven't made that shift yet."*
>
> **Jo Bibby**, Director of Strategy, The Health Foundation

The selected examples are presented in four broad categories: self-care, patients as experts, shared decisions and choice. While it is unlikely that the UK can 'cut and paste' these approaches, they help expand the limits of possibility and reveal where parts of the NHS's future may lie.

Summary of overseas examples



Scaling Up Shared Decision-Making, USA

The Health Decision Sciences Centre at Massachusetts General Hospital has created a streamlined process whereby doctors in primary and secondary care can 'prescribe' a patient decision aid through their electronic medical record. The patient can then access the tool outside of the consultation to facilitate better shared decision making.

Participatory Women's Groups, Bangladesh, India, Malawi and Nepal

Participatory learning and action groups empower local women to identify health problems around childbirth, then find and implement their own solutions. Results across over 100,000 births showed dramatic reductions in maternal and neonatal mortality.

Respectful Maternity Care, Nepal and Nigeria

A national standard across Nigeria and Nepal, this approach centres on using real-life experiences of mothers to challenge professional mindsets and create an impetus for frontline teams to improve services. One NHS trust has already successfully adopted it following failures in care.

Care Companion project, India

India's largest cardiac hospital is training patients' carers through a programme of teaching, certification and hands-on work on the ward during the patient's stay at the hospital. This gives carers the skills to better look after their family member when back at home.

Patient held records, Denmark and Malawi

Using e-records or paper, some countries are turning the relationship of patients to their data on its head, giving partial or complete ownership of medical records to the individual.

Just Ask Campaign, Denmark

Denmark created a programme to drive population-wide change in the relationship of patients and professionals. This involved mass distribution of tools supporting and prompting patients to ask more questions and overcome 'white coat silence'.

TASO, Uganda

TASO serves around 100,000 Ugandans with HIV per year through a network of 11 patient-run HIV/AIDS service centres around the country. Their 'expert clients' manage drug distribution, conduct home visits and educate other patients on better managing their condition and improving livelihoods.

Patient First Ambassadors, Australia

Designed to create a step-change in patient understanding of their rights, responsibilities and ability to make informed choices, volunteer patients were recruited and trained to discuss these aspects of care with their peers on outpatient wards.

UK examples of these principles in practice in the NHS are also given. On self-care, the work of NHS Fife's 'One size fits one' approach is highlighted, where personal care for older people is provided by a network of 'micro-providers' (local people or even neighbours) to reduce hospital stays and offer more appropriate, caring services. On shared decision making, the use of direct payments in social care and personal health budgets in the NHS is outlined, through which patients are being given control of the money that is used to fund their care. On choice, England's experience of eliminating waiting times for treatment over six months is described, and the effect that transparency and provider choice had on achieving this. On patients as experts, the work of the University of Central Lancashire to systematically involve patients and carers in medical education is summarized, as well as the work of the Expert Patients Programme.

Overseas examples point some of the way, but the biggest challenge for the NHS is to go beyond isolated initiatives to a whole-system effort. Government has been right to set NHS England the challenge of becoming "dramatically better" at involving patients and their carers.[1 2] There has been much good work to achieve this, but much more is still needed if "professionals are to come off their pedestals, and patients are to get up off their knees" (Robert Johnstone, International Alliance of Patients' Organizations).

> *"On patient choice, I think the UK is ahead of many other countries. On patient representation, we're in a good position too. Where we lag behind is the cultural change needed in frontline care, which is a pity because that's the most important part"*
>
> **Angela Coulter**, Director of Global Initiatives, Informed Medical Decisions Foundation

Some of the key lessons from the overseas examples, which should inform this bigger whole-system effort, include:

- To see patients and the community as assets, rather than just sources of need
- To adapt approaches to local contexts, and experiment
- To change patient and professional attitudes by working from the top-down and bottom-up
- To focus on equipping patients with new skills and tools, rather than just 'informing' them

Drawing on these lessons, four actions are suggested for policy and practice to step up to the scale of Government's "dramatically better" ambition for patient empowerment:

1. **Make empowering individuals in their own care a top political priority – and align incentives for a whole-system effort across the health and care sectors**
2. **Revive the revolution in decision support tools as part of a systematic drive on shared decision making led by government, the NHS and professional bodies**
3. **Give patients co-ownership of their records, not just access**
4. **Encourage patients to ask more questions about their care, through a national campaign targeted at people with long-term conditions and greater access to structured education on self-management.**

> *"The goal is to change the clinical paradigm from "what's the matter" to "what matters to you"*
>
> **Susan Edgman-Levitan**, Executive Director
> John D Stoeckle Centre for Primary Care Innovation, Massachusetts General Hospital

Part II: Global leadership

Though there is a great deal the UK can learn from others, at a global level it is clear that much, much more needs to be done in other countries too. Rigid and hierarchical systems of care are still the norm across most of the world, driven by poor access, lack of health literacy and powerful elites.

Historically, the UK has played an important role in advancing the patient and public involvement agenda internationally. Part II of this report outlines a number of successful initiatives and features of the British health system that are guiding other countries' approaches. These include:

- Patient focus consistently enshrined across national policies
- Transparency of performance and decision making at local and national levels
- Patient involvement at all stages of health research
- An infrastructure to support patient leadership
- An appetite for experimentation

> *"We believe that the UK can play a very strong role in advocating for other countries that are developing their health systems from the ground up to make sure that patient empowerment is built in from the beginning rather than bolted on towards the end"*
>
> **Linda Craig**, Operations Director, International Alliance of Patients' Organizations

Government should aspire to continue the leadership provided by the UK in the past by offering British expertise to countries that are still developing this agenda, as well as advocacy through intergovernmental bodies. Three actions would make a major difference to the UK's contribution globally:

1. **Bring together the Department for International Development's existing work strengthening health systems with the expertise of British institutions working to empower patients**
2. **Lead efforts to fill critical knowledge gaps about patient empowerment, most importantly its value for money**
3. **Advocate for intergovernmental bodies to embed patient empowerment across their health work, in particular the World Health Organization and United Nations**

Patient empowerment is not just an imperative for industrialised nations, nor is it primarily for a young, articulate minority. Although for some people empowerment will still mean wanting professionals to take decisions for them, it is those with the least power now that have the most to gain. This applies equally to low, middle and high income countries, and across physical, mental and social needs.

> *"The power of a testimony from a family member or patient to galvanise change is absolutely huge. Statistics change the head, but the patient sharing their story changes the heart. A lifetime of practice can be changed by that sort of exposure"*
>
> **Liam Donaldson**, WHO Envoy for Patient Safety

What this review involved

This review was established by six All Party Parliamentary Groups (APPGs) to consider what the UK could learn from abroad about patient empowerment and what we could be doing, in turn, to support other countries to empower patients in their health systems.

It comprised two oral evidence sessions, held in the Houses of Parliament in January 2014 to hear from leading figures from the NHS, civil society, academia and international governing bodies. A call for examples, evidence and case studies from around the world was launched, which received 40 submissions – including over 100 case studies of innovative programmes. A literature review was also conducted, focussing on systematic reviews of evidence relating to patient empowerment (and a variety of related terms).

What is 'patient empowerment'?

The concept and terminology of 'patient empowerment' are complex and contested. Are patients 'empowered', 'engaged', 'involved', or 'activated'? Should 'patient' still be used or replaced with 'citizen', 'service user' or simply 'person'? How should carers/care-givers/friends and family be included?

'Patient empowerment' is used in this report because it is succinct and found to be most comprehensible to a global audience. It has its shortcomings – notably that it does not explicitly recognise carers and for some 'patient' is a loaded term – but no language has yet emerged that is at once concise, value-free and sensible to the non-specialist.

Semantics aside, the emphasis of this review is primarily on the role of people who receive health or care services (and their carers and families). This includes people with physical and mental health needs. Less attention is given to the involvement of the wider public (citizens) in local planning and priority setting, vital though this is to the need to get health across all policies and move away from societies that "actively market unhealthy lifestyles".[9]

In practice this means the review focussed on interventions that resulted in patients or their carers:

- Better understanding their condition
- Participating in making decisions about their care
- Being supported to better self-manage their health and treatment
- Expressing their views and preferences in a way that makes a meaningful difference
- Feeling confident to ask questions and challenge professionals and organisations
- Having the chance to join networks or groups of other patients in similar circumstances.

A parallel 'empowerment' movement also exists in the social care sector. While social care was not the main focus of this review, there is clearly a significant overlap with health needs and services. Thus some lessons have been drawn from examples that could be classed as social care, and some of the review's recommendations will have relevance to both sectors.

Why patient empowerment matters

Involving patients in their own care improves quality and is vital to the sustainability of health systems around the world. Although a complex concept to define strictly, patient empowerment is now widely recognised as a fundamental pillar of healthcare for the 21st century. The challenge is agreeing how to put it into practice.

Engaging people in their own care is an important goal in itself, and a key component of high quality health services.[3] Recent examples from a number of UK hospitals have provided shocking reminders of the neglect and ill treatment that can result when patients' perspectives are not heard.[4] Yet such examples are far from a uniquely British problem, with health systems around the world seeking to create more 'person-centred' services in response to a lack of safety, dignity and autonomy for their patients.[5 6 7 8]

Patient empowerment is also seen as a solution to many of the most pressing problems facing modern healthcare. These include the rising burden of chronic diseases; ageing and end of life care; the need to encourage healthier lifestyles; and the challenge of coordinating care for people with multiple complex conditions. For all of these issues, greater self-management and individual responsibility are held as important ways of designing health services able to sustain quality under growing pressures.

> *"Empowered patients aren't a nice to have, they're fundamental to the survival of the NHS"*
>
> **Luke O'Shea**, Head of Patient Participation, NHS England

Reviews of the evidence on patient empowerment show that the degree to which patients are involved in their care has a significant impact on the quality of their treatment, and can also make a major difference to the cost.[10] Summary analyses of studies on interventions to better inform and involve patients in their care show that, on the whole, they lead to improved experience, lower dependence on health services, better adherence to treatment and, in some cases, measureable improvements in health outcomes.[11 12]

Table 1. Summarised findings of systematic reviews on effectiveness of strategies to inform, educate and involve patients in their treatment [13]

	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

Reproduced from Coulter A, Ellins J (2007) Effectiveness of strategies for informing, educating, and involving patients. British Medical Journal 335:24–7, with permission from BMJ Publishing Group Ltd

Table 2. Benefits of patient empowerment – some examples

Healthier behaviours
Motivational interviewing (MI) is a technique to facilitate behaviour change by drawing out a patient's own motivations and goals, rather than imposing those of the health professional. By placing greater importance on the patient's autonomy, these techniques outperform traditional advice-giving in terms of improving health behaviours and adherence to recommendations. This effect persists even when MI is used in brief consultations. [14 15] It is also easily adapted for use by non-clinicians, such as local patient and peer support groups.
Greater satisfaction
Personal Health Budgets take care planning a step further, giving people with long-term conditions control of the money used to fund their care. A three-year pilot of over 2000 patients across England found they improved quality of life and psychological wellbeing for patients and carers, with the biggest improvements for those with the most complex problems. Budget holders also spent less time in hospital.[16]
Better decisions
Patient Decision Aids (PDAs) are tools to help people make important decisions about their care – particularly when there is more than one option. Patients are guided in balancing information about the benefits and risks against their personal preferences, with the aim of improving shared decision making with their clinician. Studies into the effects of PDAs show a reduction in elective procedures averaging 21per cent, while delivering an improved experience with no adverse effects on health outcomes.[17]
Sustainable services
The NHS Expert Patient Programme (EPP) aims to equip people with long-term conditions with the information and skills to better self-manage their health. EPP generally consists of a series of six weekly sessions, facilitated by a tutor and alongside patients with the same condition. EPP is now available for over a dozen chronic conditions, with participants reporting greater confidence and self control, and reduced dependence on healthcare.[18]

In short, well-informed, supported and empowered patients serve the interests of individuals and the health system.

The UK, along with the rest of the world, faces a number of common barriers to empowering patients. 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.[19 20] Second, research evidence on patient empowerment, while much strengthened over recent years, still contains important gaps – most importantly whether the interventions that work offer value for money when done on a large scale.[21] Third are practical barriers such as 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.[22]

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 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.[23] This highlights the importance of holistic, whole-system change built on a shift in professional attitudes and behaviours.[24] Without this, there is a danger that patients will become empowered only to be discouraged when they encounter services that don't embrace this new relationship.[25] [26]

> *"There are very few people who are arguing against the idea of patient empowerment. It's the practicalities of making it a reality where there's often resistance."*
>
> **Linda Craig**, Operations Director, International Alliance of Patients' Organizations

International examples to inspire change

Over 100 examples of patient empowerment initiatives from high, middle and low income countries were submitted to this review. A theme running through all of these was patients and their carers taking on roles well beyond that of passive recipients of care. The following eight best represented these expanded roles, showcasing expanded ways of encouraging self-care, patient expertise, shared decisions and informed choices. Though it is unlikely the NHS can directly 'cut and paste' solutions from India, Uganda and the United States, these examples help to expand the limits of possibility. For each category, an example of how these principles are already at work in the UK is given.

Self-care

It is widely recognised that the vast majority of care is delivered by people themselves, not professionals. Self-management support programmes for chronic conditions are becoming more common across the world. The following two examples extend these principles even further – putting patients right at the core of delivering care for themselves and others.

TASO - The AIDS Support Organisation (Uganda)

In HIV care, the use of 'lay health workers' has been a major factor in the scaling-up of anti-retroviral therapy (ART) to large populations across Africa. TASO serves around 100,000 Ugandans with HIV per year through a network of 11 patient-run HIV/AIDS service centres around the country. Each centre is staffed by up to 50 'expert clients', managed by a professional coordinator. In addition to drug distribution, the clients conduct home visits in which they educate other patients on the dos and don'ts of being on ART, make sure they are storing drugs correctly, have appropriate hygiene and are adhering to treatment. They can also connect them to, and follow up from, livelihood training programmes operated by TASO. Though born of necessity, TASO finds fellow patients are better than professionals at achieving behaviour change among their peers.

For more information, visit **www.tasouganda.org**

Participatory Learning and Action Groups (Bangladesh, India, Malawi and Nepal)

Around 270,000 women worldwide die every year from complications of pregnancy and childbirth, and nearly three million infants do not survive the first month of life. Participatory women's groups are a community based approach to tackling this problem. The groups empower local women to identify and prioritise health problems around childbirth, then find and implement locally appropriate strategies to overcome these. Self-directed and using participatory methods such as voting, role-play and storytelling, the groups boost women's confidence to talk about their problems and effect change in their own and each other's behaviour.

A meta-analysis of seven randomised controlled trials of the approach in four countries (covering over 100,000 births) has shown dramatic reductions in maternal and neonatal mortality, down 37 and 23 per cent respectively. A small-scale trial is now planned to adapt this approach to the UK – focusing on families in deprived urban areas.

For more information see Prost et al. (2013) *Women's groups practicing participatory learning and action to improve maternal and newborn health in low-resource settings: a systematic review and meta-analysis.*[27]

How this is working in the UK

The UK has a vibrant voluntary sector, but it can often be poorly integrated with formal services. One area that is trying to integrate community assets into the core health system is NHS Fife. Their 'One size fits one' approach turns community resources into micro-enterprises to better care for older people and reduce hospital admissions. Central to the project is supporting staff to have personal outcomes-based conversations with people and helping to build the individual's and community's self-reliance and resilience. For example, if an older person breaks their wrist and is unable to look after themselves, instead of being admitted to hospital micro-providers are responding by providing meals and personal care to keep the person in their home. In another case, what mattered to an elderly woman living alone was cups of tea and chats and being able to visit the local shops. Putting this in place for this individual led to early discharge from the day hospital she was attending and led to a cost savings. This means care specific to the patient's needs, delivered to them by local people they may already know, with fewer delays in discharges or lengthy hospital stays.

For more information, see the full case study on NHS Fife on the Health Foundation's website.[28]

Experts

Describing patients as 'experts' is controversial, but who can understand the experience of an illness better than the person with it? The following two examples show two aspects of this concept that have been given less attention – training up family members to better care for patients at home, and using the unique lived experiences of service users to directly challenge how care is delivered.

Care Companion programme (Narayana Hrudayalaya Hospital, India)

The Care Companion programme aims to empower the caregivers of at-risk patients with the skills they need to take better care of their loved ones back at home. On admission to the hospital – the world's largest cardiac centre - the patient's main carer is identified and offered the chance to enroll in the programme. Then, while the patient goes through the pre-operative stages and surgery, the caregiver undergoes classroom training sessions via interactive videos. This is then followed up by hands-on, in-person training in the post-operative ward when the patient is in recovery. The caregiver is then certified – following an exam – and supervised working on the ward until the patient is discharged. The programme is now operating across two hospitals in the group, with plans to roll out across all 27 in the chain in the coming months. The hospital's leaders say that 100 per cent of trainees report the programme as 'very useful', that they integrate very well into the day-to-day running of the hospital and are resulting in a repositioning of family members as an integral part of patient care (while reducing the workload for hospital staff).

Respectful Maternity Care (Nigeria, Kenya, Bangladesh, Yemen and Nepal)
Respectful Maternity Care (RMC) is a package of measures designed by an international 'community of concern' convened by the global advocacy network White Ribbon Alliance to inspire midwife-led change in the treatment of women giving birth. The approach centres on using the perspectives and real-life experiences of mothers to challenge professional mindsets and create an impetus for frontline teams to improve their care. To date, midwives have been the agents of change in the process. Key components of the intervention include:

- Presenting staff with local patient stories of poor care and neglect
- Agreeing and promoting a clear charter of rights that all mothers and midwives should be aware of and expect during their care
- Setting local problems against the global context of poor care and abuse of child-bearing women
- Devising and implementing midwife-led changes in practice

RMC is now en route to being adopted as the national standard of practice for Nigeria and Nepal. Although it was designed to reduce high rates of maternal mortality in low and middle income countries, recently it has been attracting interest within the NHS. One English hospital trust successfully adopted it, alongside a package of other measures, following an investigation into poor maternity care. The Royal College of Midwives, as well as a number of London hospitals, are now conducting work to assess RCMs potential for wider implementation across the UK.

For more information, see *A Guide for Advocating for Respectful Maternity Care*.

How this is working in the UK
Although not yet normalised across medical education, a number of UK medical schools have integrated patient perspectives and expertise into the core of health professionals' training. Comensus (Community Engagement and Service User Support) is a service user and carer-led team that work to systematically involve patients across the University of Central Lancaster's Faculty of Health. Course leaders work to deploy the team's members across their curricula, but there are also entirely user-designed and led modules.

For more information see the Health Foundation's report *Can patients be teachers?*[29]

Another dimension of the patient as 'expert' involves giving people the knowledge and skills to be in control of their own condition. This is the focus of the Expert Patient Programme, which has been operating and expanding for more than 10 years across England and Wales. See Table 2 (page 11) for more details.

Shared decisions

Shared decision making is at the core of patient empowerment. It focusses on good communication and ensuring treatments are based on the patient's preferences and best available evidence. The following two case studies have been reproduced from 'Partnering with Patients, Families, and Communities for Health: A Global Imperative', a report published for the World Innovation Summit for Health (WISH) 2013, an initiative of Qatar Foundation (available at **www.wish-qatar.org/reports/2013-reports**).[30]

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 per cent 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 has shown 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 organisations, hairdressers, media, unions, and businesses.

For more information, visit **www.just-ask.dk** and see Patient Handbook: *A Patient's Guide to a Safer Hospital Stay.*[31]

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 'prescriptions' have been ordered to date, with initial results from an evaluation showing strong take-up and increased patient satisfaction.

For more information, visit **www.massgeneral.org/decisionsciences**

How this is working in the UK
Personal budgets and direct payments have been used in social care 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 per cent of social care service users in England now use personal budgets or direct payments. The concept is being expanded to the NHS, starting with NHS Continuing Healthcare where from October 2014 eligible people will have a 'right to have a personal health budget'.

For more information, visit **www.personalhealthbudgets.england.nhs.uk**

Choice

In addition to treatments, people are routinely exercising other choices about health and healthcare – whether they choose to visit the emergency department, GP or pharmacy, for example. Or what lifestyle or health products to buy. Various attempts have been made in the UK to introduce new ways for people to access healthcare, but the key is having useful information and knowledge to guide health choices. Two overseas examples struck up particular debate.

Patient-held health records (Denmark and Malawi)

While the UK works towards a target of patient access to their medical records by 2015, a number of countries have taken a more radical step – allowing patients to interact or even own their records.

Denmark operates one of the most widely used and sophisticated electronic health record systems in the world. Since 2003, a national eHealth portal has given all citizens access and partial editing rights to a central shared individual record. Users can find information on their previous treatments and diagnoses, book appointments with GPs, renew prescriptions, survey local provider waiting times and quality ratings and connect to patients/carers like them through 'chat' facilities. Citizens currently visit their health portal an average of seven times per year, and the disparity in the age profile of users of the system seen initially has been eliminated.

Malawi's 'frugal' equivalent of this model shows that high-tech solutions are not the only way of giving patients access to their health records. All Malawi citizens are issued with a physical 'health passport' which they keep themselves and take to every hospital visit. The passports are an integrated record of the patient's health conditions, outpatient appointments, a summary of their in-patient consultations and immunization records. The records travel with the patient, rather than being held by the provider, and visits begin with patient and clinician reviewing history and progress together. Health passports help patients to be more involved in their care and mean a provider can see their records wherever they seek care. Although Malawi is now beginning to introduce an electronic system of records, they still plan on running this alongside the health passport system, so that records will still be held by the patient as well as the provider.

Patient first ambassadors (Australia)

Western Australia's Patient First Ambassadors were introduced to combat the seemingly insurmountable task of changing how patients saw their role and create a step change in people's health literacy. Volunteer patients were recruited and trained to engage with patients in hospital outpatient departments – discussing informed consent, making decisions, privacy and managing medications with them. They were equipped with a Patient First Handbook to distribute to patients, which also contained information on rights, shared decision making, understanding the risks of treatment, staying safe in hospital and medication safety.

For more information, see the Australian Commission on Safety and Quality of Healthcare's report *Patient-centred care: Improving quality and safety through partnerships with patients and consumers.*[32 33]

How this is working in the UK

Access to healthcare is a critical component of patient empowerment, with choice between providers an important component of this. England's experience of increasing choice of provider has been complex. One of the most important lessons learned has been that, while few patients may take advantage of having this choice, transparency of performance data and the threat of losing patients to others can still have a significant effect on provider behaviour. This was the case in the rapid fall in people waiting more than six months for treatment that took place between 2002 – 2005 (from 250,000 patients per year, to zero). The reduction was motivated by two initiatives. Firstly, a policy whereby patients waiting more than six months could opt to transfer to another hospital for immediate treatment. Second was the introduction of the first Independent Sector Treatment Centres.[34]

More recently, UK providers and developers have been among the leaders in expanding access to mental health services through computerised self-help and peer-support. Services like **beatingtheblues.co.uk**, **bigwhitewall.com** and **fearfighter.com** are helping to educate people about mental health and expand access to group, talking and cognitive behavioural therapies at extremely low cost.

What the UK can learn from overseas

The examples submitted to this review share a number of striking features that warrant further consideration within the NHS. These include seeing patients and the community as assets rather than a source of need; the power of collective action by groups of patients; the importance of local context and adaptation; the need for every level of the system to act; and focussing on educating and engaging – rather than just informing – patients.

The first lesson from the submitted examples is the benefits of harnessing resources beyond the formal care system. This means seeing patients and their carers not only as a source of need but also assets that can be used for direct care of themselves and others; providers of information and motivation for their community; and change-makers within health services themselves.

In the UK some of these ideas have become familiar through the Coproduction movement as well as the Department of Health's work on self-care.[35 36 37] These have shown how patients and their carers already provide the vast majority of care, with health professionals making up just a small fraction of the 'labour supply'. Some of the overseas examples show these principles taken to the next level, with scaled-up models of care where patients make up a central component of service provision, improvement and innovation. Low and middle income countries seem to be leading the way with this.

> *"Where you don't have a well-resourced medical infrastructure you have to be much more creative about how you mobilise the resources of your wider population to promote health and wellbeing. We have much to learn from other countries in this respect, not only in making limited resources go further but in the huge benefits of embracing 'people power' alongside formal healthcare"*
>
> **Jeremy Taylor**, Chief Executive, National Voices

A related second lesson is the power of groups. Whether helping peers within the group (as with the participatory women's groups) or harnessing collective action to help others (such as TASO Uganda), patients are achieving things together that formal services cannot. One of the particular strengths of groups appears to be the credibility that lived experience confers, allowing patients to overcome some of the resistance that health professionals often encounter.

The UK has its own experience of this through the success of groups such as Alcoholics Anonymous and Weight Watchers, both of which have found that difficult behaviour changes can be more easily achieved using peers as well as, or instead of, professionals. As the UK continues to struggle with problems such as poor mental health, unhealthy lifestyles, loneliness and a lack of good care for older people, how else might we adapt these models, inspired by what has been possible at home and abroad?

Lesson three is that local context is paramount. A feature of many of the examples – from both high and low income countries – is that they do not have their origins in a detailed survey of the literature followed by implementation of the most effective, evidence-based solution. Rather, their experience is more commonly one of trial and error, adaptation and improvisation, often enhanced by the inclusion of patients and families into the design process. Patient engagement interventions are difficult to evaluate because of the variability of patient characteristics that can contribute to success or failure and the difficulty of randomizing participation. This limits the transferability of evidence but adaption of common attributes of success can be shared. It is also important to remember that what good evidence does exist – while mostly positive – is still mixed. Empowering patients will not always improve health outcomes, nor decrease service cost. In these circumstances local services and patients are right to experiment and to adapt what others have done.

A fourth lesson is that every level of the health system has something they can contribute to see patients empowered on a bigger scale. Two themes that commonly appeared in successful large-scale initiatives were a focus on motivating individual professionals and patients through their own experience, and the vital role that government policy and professional bodies can have in driving change. This highlights the challenge of needing bottom-up and top-down action.

> *"Whatever we do, it needs to be a holistic approach – equipping individuals to manage their care, as well as supporting professionals to have the skills needed to play a more enabling role rather than 'diagnose and treat'"*
>
> **Jo Bibby**, Director of Strategy, The Health Foundation

Finally, but perhaps most important of all, is the focus so many of the successful examples have of putting skills and tools in the hands of patients. The link between health literacy and health outcomes is well established[38], but often interpreted narrowly as simply giving patients information. Being informed is just part of the formula to being empowered, and programmes such as the Care Companion project – as well as UK initiatives such as the Expert Patient Programme – show how much more could be done.

> *"Professionals need to come off their pedestals, but patients also need to get up from their knees"*
>
> **Robert Johnstone**, Board Member, International Alliance of Patients' Organizations

Recommendations (Part I)

Much progress has been made by recent governments to empower patients in the UK, but many more changes are needed to meet the goal of becoming "dramatically better". The following practical actions suggest ways of applying the lessons from other countries to accelerate progress in the UK.

1 Make empowering individuals in their own care a top political priority – and align incentives for a whole-system effort across the health and care sectors

The UK has done more than most countries to involve patients in making decisions about local services and structures. Far less progress has been made to change people's role in their own care. Changing the role of individual patients in their health and treatment is a much greater challenge, but would make a much greater difference to the quality and sustainability of UK health services. Political and health service leaders should be explicit in making this personal, front-line dimension of patient empowerment their top priority for reform. A whole-system effort is needed to achieve this. Reviewing how incentives across the health and social care systems could be better aligned to support this would be a helpful next step.

2 Revive the revolution in decision support tools as part as a systematic drive on shared decision making led by government, the NHS and professional bodies.

Patient Decision Aids are among the best evidenced ways of involving patients in making shared decisions about their care. A programme to develop a suite of PDAs for common conditions received significant investment from government, yet progress appears to have slowed since the Health and Social Care Act 2012 was introduced – a result of reduced capacity to manage the programme and complexities transferring its administration from the Department of Health to NHS England. Renewed priority and investment is needed to ensure this programme continues at pace.

At the same time, a revolution in the take-up of PDAs will need more than just making these tools available. Widespread change needs a bigger cultural push on shared decision making with much stonger leadership from professional bodies and professionals themselves to better partner with patients.

3 Give patients co-ownership of their records, not just access.

NHS England is working towards a goal of giving every patient the ability to view their GP medical records by 2015. The experiences of other countries suggest that access alone is unlikely to drive significant use of records by patients, but that some degree of co-ownership or interactivity with their health information can. While working towards the 2015 goal, all four home nations should already be aiming further, with plans for systems that better reflect the principles of true partnership with patients. This should be alongside investment and training for professionals to facilitate adoption and use of these shared records.

4 Encourage patients to ask more questions about their care, through a national campaign targeted at people with long-term conditions and greater access to structured education on self-management.

Large-scale systematic efforts (such as JustAsk in Denmark) and successful local British initiatives (such as the Health Foundation's MAGIC programme) show that patient and clinician attitudes can be changed over time to embrace more equal partnership. Government should seek to apply these lessons at a national scale through a campaign targeting people with long term conditions to develop the confidence to ask more questions of their clinicians – and prompting professionals to encourage better conversations too. Investment should also be increased to increase access to high quality structured education for people with long term conditions, such as the Self-Management Programme and Expert Patient Programme.

Patient empowerment: The global picture

Though there is a great deal the UK can learn from others, at a global level it is clear that much, much more needs to be done in other countries too. Rigid and hierarchical systems of care are still the norm across most of the world, driven by poor access, lack of health literacy and powerful elites. This pattern is changing, however, with the greatest opportunities to be found in emerging economies who, free from some of the baggage of mature health systems, have the chance to embed patient-centredness at their foundation as they develop.

Many contributors with an international perspective on patient empowerment commented that the NHS was, despite its flaws, among the better systems in the world in terms of patient involvement and engagement. Objective international comparisons support this observation.[39] While there is still a strong case for radical change in the UK, it is clear that patient empowerment is a global issue, not just a British one.

From a global perspective the greatest barriers to patients having choice and a voice in their care include:[40 41]

- Poor access to, and limited capacity of, local health services
- Low levels of health literacy
- Social exclusion of marginalised or low status groups
- Corruption and domination by powerful elites
- Few civil society groups with the capacity to advocate for patients
- Little formal acknowledgement of patient rights

There are many attempts to overcome these barriers in low and middle income countries. Accountability and community participation are now widely accepted components of state-building and international development, with significant attention and investment by individual governments, the World Bank and World Health Organization, among others. [42 43]

Much more is needed, however, as the general picture remains one where those at the top determine the priorities and shape the services to address them. Patient advocacy and civil society in most low and middle income countries is comparatively weak.[44] Surveys – which only scratch the surface of people's potential contribution – are still viewed as the dominant method of engaging patients and local communities. The goal of appropriate, accessible, empowering healthcare is still a long way off for the vast majority of the world's population.[45]

> *"Patient empowerment isn't an add-on. It leads to better services designed in a way that families are able to access"*
>
> **Louise Hulton**, Director, Evidence for Action

There is reason for hope, however. Driven partly by necessity, partly by new technology (such as mobile phones), many low and middle income countries are forging a different path. In response to intolerable levels of unmet need, new models of care are being adopted where patients are not merely consulted but deployed as a fundamental arm of health service planning, design, delivery and evaluation.[46 47] While much of this is making up for an extreme scarcity of health workers, it is creating – in places - an indelible realisation of the importance of the patient role.[48] This may well lead to a rapid convergence – perhaps even a 'leapfrogging' – of low, middle and high income health systems on patient empowerment-related dimensions of quality.

These changes are not and will not be driven by external actors, but by the countries and communities themselves. Development agencies, donors and high income nations should be careful not to 'mandate' patient engagement or public participation in low and middle income health systems, as there is a strong chance this may backfire or normalise hollow exercises.[49] Nonetheless, there are things that high-income countries – including the UK – can do to support and encourage this trend.

> *"We believe that the UK can play a very strong role in advocating for other countries that are developing their health systems from the ground up to make sure that patient empowerment is built in from the beginning rather than bolted on towards the end"*
>
> **Linda Craig**, Operations Director, International Alliance of Patients' Organizations

The UK has in the past made several significant contributions to support the patient empowerment agenda at an international level. First, British institutions and leaders have been the source of much of the best research around person-centred care, from landmark reports such as An Organisation with a Memory to long-term programmes of evidence generation and review, such as those led by the Health Foundation.[50 51] Secondly, the UK has campaigned for greater priority of patient-centred care in international governing bodies such as the World Health Organization, resulting in important milestones such as the London Declaration on Patient Safety and the formation of the Patients for Patient Safety Programme. Thirdly, the NHS has introduced a number of initiatives that other countries are looking to as innovative models to adopt or adapt, as the next chapter outlines.

The World Health Organization's Patients for Patient Safety Programme

Patients for Patient Safety – a core part of WHO's Patient Safety Programme - brings together patients, providers, policy-makers and those effected by harm to improve healthcare safety through advocacy, collaboration and partnership.

The programme has more than 300 Patients for Patient Safety Champions in 53 countries, the majority of which are patients or family members affected by healthcare harm. The champions integrate the expertise of patients and families into the work of the WHO Patient Safety Programme, as well as partnering with other organisations committed to improving safety locally, nationally and internationally. Their work spans all types of engagement, from story-telling to raise awareness and catalyse change; to facilitating implementation of WHO policy; to contributing to education, research and policy development.

For more information, see
www.who.int/patientsafety/patients_for_patient/en/

What others are learning from the UK

While there is much for the UK to learn from others about empowering patients, our review also found many ways in which the NHS is seen as in the vanguard of this issue internationally. Overseas contributors highlighted a number of British policies and practices that were informing other countries' approaches. Strictly speaking, many of these are aimed at involving the public in health services, rather than patients in their own care. This may well reflect the UK having made greater progress in reforming structures than changing the patient-clinician relationship.

Patient focus enshrined

National policies provide a coherent framework and narrative of the priority given to patient-centred care. From the formal rights and values set out in the NHS Constitution; to NHS England's mandate to "ensure the NHS becomes dramatically better at involving patients and their carers"; to the cross-cutting principle of "no decision about me without me"; to the inclusion of patient experience as one of the four dimensions of service quality in the NHS Outcomes Framework; and a national Quality Standard on patient experience.[52 53 54 55] These help to institutionalise the rights and centrality of patients across the health system.

Transparency

Health system accountability is a growing priority of governments the world over. A number of ways in which the NHS has tried to realise this were highlighted as generating significant interest abroad. One of these was NHS England's practice of holding its board meetings in public, with an audio-visual live stream of proceedings broadcast in real time over the internet. Another was the availability of information about local services – including performance ratings, patient feedback and health advice - through England's NHS Choices or Scotland's NHS Inform.

Patient involvement in research

Since 2006, the UK's National Institute of Health Research (NIHR) – the £1 billion research funding and coordination body – has required all research programmes it funds to actively engage patients at every stage. This includes funding a specialist network (INVOLVE) to provide a central resource of patients and members of the public interested in being involved in how health research is commissioned, undertaken, communicated and used. In addition, all research grant applications to NIHR must specify how they have involved and plan to involve patients throughout their study. A similar requirement has recently been adopted by the US National Institutes of Health (NIH), among others.

An infrastructure for patient leadership

The UK benefits from strong civil society organisations that are able to advocate for patient interests. Non-governmental organisations such as Macmillan Cancer Support and National Voices provide a bridge between frontline experiences and national decision-making. All four home nations also fund networks of local patient groups, which provide a formal route for participating in decisions about health service policy and planning.

An appetite for experimentation

Although spreading good practice across the system remains a weakness, local NHS organisations are perceived as fertile ground for innovations. The recent pilots of Personal Health Budgets, where patients are given control of their own healthcare budgets, were one example cited.

Recommendations (Part II)

Historically, the UK has been an important leader for the global patient empowerment agenda. This is a role that government should aspire to continue playing, by working to change intergovernmental organisations and offering British expertise to countries that are still developing this agenda. Three actions would make a major difference to the UK's contribution globally:

1 Bring together the Department for International Development's existing work strengthening health systems with the expertise of British institutions working to empower patients.

DFID assists many countries to strengthen their health systems and develop good governance and strong civil society. Its capacity to advise in these areas is becoming increasingly important as it shifts from financial to technical support in some regions, and partner countries' priorities move from vertical programme goals to universal healthcare. However, there are currently few links between DFID and some of the NHS institutions and large patient organisations that could provide useful expertise in these areas. Bodies such as Healthwatch England, NHS Choices and NHS England have yet to follow the lead of NICE and Public Health England in developing international programmes to link with overseas governments that wish to learn from them. Equally, grassroots patient organisations such as Diabetes UK and the British Heart Foundation could also make a major contribution by sharing their expertise.

A step-change in cooperation between DFID and these bodies could produce valuable synergies for all: DFID would have access to a new pool of expertise; NHS and patient organisations would gain an opportunity to build international links; and overseas partners would have the chance to learn directly from the successes and failures of the UK experience.

2 Lead efforts to fill critical knowledge gaps about patient empowerment, most importantly its value for money.

The evidence base on patient involvement and engagement has developed significantly in recent years, thanks in part to research led by British universities and institutions. Major gaps remain, however, particularly around:

- Evidence on the value for money of effective patient empowerment initiatives, particularly the financial costs and benefits of large scale interventions
- Developing and agreeing standard indicators to measure the extent to which a service, organisation or country is partnering with patients
- Operational tools to support change in frontline practice.

Budget pressures on healthcare mean that value for money is a major consideration for health systems around the world. The UK could generate significant benefits for itself and other countries by reviewing and improving evidence on the economic impacts of patient empowerment. The National Audit Office would be a powerful, well-placed leader for this work.

3 Advocate for intergovernmental bodies to embed patient empowerment across their health work.

The UK played a crucial role in the establishment of the Patients for Patient Safety programme in the World Health Organization. This innovative model of building patients' perspectives and energy into an intergovernmental organisation has been a great success, however the ideas behind it have been slow to spread to other parts of the organisation. The UK should advocate for the WHO to review its structure and operations to determine where else patients and their families could be more deeply embedded and involved.

Furthermore, in its involvement in formulating the UN's Post-2015 global development framework, the UK should also make the case for the importance of strengthening the patient role in achieving the proposed Universal Healthcare goal.

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