An Office for Patient Outcomes

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SUMMARY POINTS

• There is a lot to be proud of in our national health and care system. Some patient outcomes are strong and much information about them is collected and made accessible to professionals and decision-makers.

• There are nevertheless areas of patient outcomes, such as cancer survival rates, where the performance of our health and care system needs improvement. While information about outcomes exists, there are significant gaps; issues of trust and reliability; there is only a very limited role for patient voice in determining what information is created and reported; and its use in sharpening accountability is unclear.

• Similar issues existed in the past in relation to information about public finances. The creation of the Office for Budget Responsibility has gone a long way to addressing these; and it is widely regarded as a success, including in relation to improving accountability.

• Other health and care systems have equivalent bodies that bring the same sharp focus to national patient outcomes. The Canadian Institute for Health Information and Australian Institute of Health and Welfare are examples.

• Creating a similar body in England – an Office for Patient Outcomes – has the potential to address many of the shortcomings in current information provision and produce sharper accountability for improving patient outcomes. This would be a low-cost, high-impact innovation, building on many of the strengths of the present system. It would substitute many of the existing features of the health and care system, and improve on them, rather than add to cost and burdens.
ABOUT THIS PAPER

This paper was written by the Social Market Foundation, developing an idea initially proposed by AstraZeneca. AstraZeneca has funded development of the report, but the Social Market Foundation retains full editorial control.

ABOUT THE AUTHOR

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ABOUT THE SOCIAL MARKET FOUNDATION

The Social Market Foundation (SMF) is an independent, non-partisan think tank. We believe that fair markets, complemented by open public services, increase prosperity and help people to live well. We conduct research and run events looking at a wide range of economic and social policy areas, focusing on economic prosperity, public services and consumer markets.
AN OFFICE FOR PATIENT OUTCOMES

Introduction

The Government has a clear objective to improve patient outcomes in the NHS. The Prime Minister has given his personal backing to a seven day NHS; and the Health Secretary has said that “this decade needs to see the quality revolution.” The Department of Health, NHS England and other agencies’ Shared Delivery Plan for the health and care system states as its vision, “We will champion the power of patients and the public through greater focus on safety, compassionate care and transparency.” Initiatives such as the Accelerated Access Review, as one example, are already seeking to enhance the role of patient voice as well as deliver outcomes – such as quicker access to innovative treatments – which patients prioritise.

The question for this paper is whether there is a case for going further in producing information about patient outcomes at a national level, available in an accessible way, for the health and care system to be held accountable for achieving these ambitions.

We ask this question in a context where, while some patient outcomes are strong, cancer survival rates, for example – according to the latest OECD data – are in the bottom third of its 34 members. Equally, there is high pressure on resources, which means that decisions about how to allocate them to a range of the different patient outcomes that may need improving are critical. Those decisions should be informed by patient voice, which in turn should be able to draw on high quality, accessible information about outcomes.

We begin by reviewing what information about patient outcomes already exists, then consider what improvements may be needed, before suggesting how an innovation like an Office for Patient Outcomes would be a powerful way to deliver these improvements.

What information about patient outcomes already exists

The health and care system has come a long way in producing more information about patient outcomes. Some examples of what already exists are:

- NHS Outcomes Framework. It covers five domains of outcomes, including for example ‘preventing people from dying prematurely’ and ‘ensuring that people have a positive experience of care’. It provides a wide suite of information, in the first instance for the Secretary of State to hold NHS England accountable for the delivery of outcomes. The outcomes framework is based on advice from the National Institute for Health and Care Excellence.

- Health and Social Care Information Centre. The HSCIC is primarily a delivery body responsible, according to the Health and Social Care Act 2012, for “the collection, storage and analysis of national healthcare, public health and social care data, including personal confidential data.” In addition to its delivery responsibilities, it also disseminates data. It is the HSCIC for example that collects and publishes the data underpinning the NHS Outcomes Framework.
Care Quality Commission. The CQC inspects care providers and publishes the results of its inspections. The CQC also aggregates from its inspections to provide broader commentary about the state of care across the system as a whole.

In addition to these bodies, the Office for Life Sciences publishes data on research and innovation activity, though it does not cover patient outcomes directly. Finally, there are standalone research projects and inquiries which create data on patient outcomes. A recent high-profile example is the study looking at whether weekend hospital admission is associated with increased mortality.

Looking across this sample of information about patient outcomes, and compared to some other public services, the health and care system deserves credit for taking seriously the task of creating information about patient outcomes – and reporting it.

At the same time, we should expect a very high level of information provision. The health and care system is the single largest public service in terms of the public funding it receives, one that most of us interact with regularly and typically at times when either we or friends and family are at our most vulnerable.

Equally, information about patient outcomes is needed to inform commissioning choices as well as patient choice – it is hard to see how the system could function without information about outcomes. Finally, it is obvious that the outcomes for which the health and care system is responsible – life, health and vitality – are the most essential of all.

The shortcomings of information about patient outcomes

In that context of why information about patient outcomes is vital, we can observe several issues in what is currently available.

- It is spread over a range of reports and reporting bodies. Even the list in the section above illustrates that range. The briefest glance at any of the websites of the bodies named will also show that, even within each body, the information it collects and reports is then further divided between different reports.

- Arguably, this is inevitable, given the complexity of the health and care system and the services that it delivers, but then coordination between the different sources of information is poor. As one example, three different bodies are responsible for designing the various questionnaires used to capture information about patient experience in the NHS, overseeing their implementation, collating and publishing the results. Patients or the public cannot locate the results from these different surveys in the same place; and neither can professionals.

- There are gaps in what is reported. Some of these are technical in nature and the reports recognise that work is needed to tackle them. But there are deeper gaps too and often there isn’t a clear scheme for how these will be filled.

- There is a limited role for patient voice in deciding what is reported. For example, the consultation for the latest version of the NHS Outcomes Framework included just four events, the invitees to all of which were specialist and professional organisations – stakeholders rather than patients or members of the public.
○ There is **limited evidence** that the information reported is being used by patients themselves to hold services or the system to account. This disengagement begins with **extremely low awareness of the presence of information** in the first place. Work done by Britain Thinks for the Health Foundation suggests that this is true even of information about GP practices, never mind more specialised or less commonly used care. Monitor previously reported that 84% of patients who registered with their GP in the last 10 years did not consider another practice at the time.

○ When patients are shown the information available, their **feedback suggests that it is not particularly useful to them** – for example, only 17% of the sample in the Britain Thinks research found the CQC ratings of GP practices were useful. This lack of public engagement suggests that, even if experts or healthcare insiders believe that enough information is available, this may be because it is designed for their use, not for the use of patients. The accountability gap remains.

○ Perhaps unsurprisingly, given the limited level of awareness and engagement with available information, there are **concerns about whether information is trustworthy**. On the whole it is not reported independently but by bodies internal to the health and care system. The recent controversy over the reliability of the study into weekend hospital admissions is one high-profile example of how there can be competing versions of the truth about patient outcomes – and no independent body helping patients and the public to decide between them.

○ Finally, in relation to much of the information that is available, it is **unclear what consumers of information can use it to do**. This links to a previous point – fundamentally, the purpose of most information provision is to assist healthcare practitioners and providers, or other bodies in the health and care system, to fulfil their functions. It does not improve accountability in any wider sense and often fails to inform even the choices that patients do have.

**Case study: public finances**

The previous section presents a wide array of concerns about the information available on patient outcomes in the health and care system. These should be seen in the context that information provision is nevertheless extensive. And it’s not as if healthcare is the only area where concerns about information provision arise.

Very similar issues about the reporting of information about public finances existed until 2010. Then the Office for Budget Responsibility (OBR) was created to address them. Specifically, information about public finances was scattered across a range of sources; there were gaps in what was reported; limited engagement with the users or potential users of information; and concerns about whether information was trustworthy.

In this context, the mission of the OBR is to provide independent and authoritative analysis of the UK’s public finances. As the OBR itself observes, “it is one of a growing number of official independent fiscal watchdogs around the world.” It has five main roles: economic and fiscal forecasting; evaluating performance against targets; sustainability and balance sheet analysis; evaluation of fiscal risks; and scrutinising tax and welfare policy costing.

In addition, there are a set of principles that underline its operation, in common with the other independent fiscal watchdogs around the world. These are summarised by the Organisation for
Economic Cooperation and Development and are used in the periodic independent evaluation of the OBR. We will return to these in the next section.

As confirmed by the independent evaluation, the OBR has been, according to a broad range of opinion, a success. Its headline judgements are critical to news coverage of the public finances and its reports a starting point to any in depth analysis. It’s very difficult to see how a future government could now abolish the OBR; and in fact there is pressure from politicians and policy experts to extend the role of the OBR.

Formally, the OBR was created under the Budget Responsibility and National Audit Act 2011; and its remit is set by Parliament through the Charter for Budget Responsibility. Finally, there is a formal – and public – memorandum of understanding between the OBR, HM Revenue and Customs, the Department for Work and Pensions, and HM Treasury stating the agreed working relationship between these bodies.

The creation of the OBR and its key characteristics of independence, transparency and a remit set by Parliament potentially point the way to how similar issues on the provision of information that used to exist in the public finances could now be tackled in the health and care system.

**Independent healthcare bodies in other countries**

While the OBR may be an instructive case study for the UK, we can also observe that there are independent bodies in other countries which are responsible for providing patients and the public with information specifically about healthcare outcomes.

The Canadian Institute for Health Information (CIHI) is one example. CIHI “is an independent, not-for-profit organization that provides essential information on Canada’s health system and the health of Canadians.” While operationally independent, it also has very strong links into government. The Board includes Deputy Ministers from provincial governments and Health Canada (the national department for health) and the Assistant Chief Statistician from Statistics Canada (the national statistics body). The Chair of the Board is a university professor.

CIHI produces thematic reports on health system performance as well as maintaining a dashboard of indicators. The full set of these includes 45 indicators. While this means that potential users of the data can access it all in a single place, the information on the full set can nevertheless be quite technical in nature. Recognising that limitation, CIHI also produces infographics and plain language versions of information on 15 indicators representing 5 themes which were settled in consultation with patients and the public.

The Australian government has taken a similar approach, creating an Australian Institute of Health and Welfare (AIHW). Its mission is described as providing “authoritative information and statistics to promote better health and wellbeing”. The Board comprises independent as well as government members. It is subject to the oversight of the Minister for Health though cannot be directed by the Minister. It is accountable to the Australian Parliament.

Practically, AIHW aggregates health data from across the health and care system. Much of the data is specialised and technical in nature and provided for a primarily professional or expert audience. Nevertheless there is a big advantage in that it is accessible in one place. AIHW in addition produces biennial reports on Australia’s Health and Australia’s Welfare – the most recent ones are Australia’s Health 2014 and Australia’s Health 2015. These are available for free online and available for purchase as class sets. In other words, they are prepared in such a way that they should be accessible to young people and students.
Designing an Office for Patient Outcomes

This paper previously mentioned that there are common principles, internationally recognised, which underpin the operation of the OBR. These may provide a useful starting point for thinking about the design of an Office for Patient Outcomes (OPO). The Canadian and Australian models form a similar body also embody many of these principles.

1. **Broad political commitment and a clear mandate:** This is vital to ensuring the longevity of a new institution; and establishing its credibility. For these reasons, the OBR, as we have already observed, is set up under legislation and works within a remit proposed by the Government and then voted on by Parliament. There seems no reason in principle why the OPO could not be set up on a similar basis.

2. **Independence and non-partisanship:** The OBR has its own board, operates at arm’s length from the Government and observes great care in sticking to its remit. These characteristics are already shared by a number of health bodies, e.g. NICE, and should be replicable for the OPO. They are critical for the OPO to win and retain public confidence as well as to be considered an independent voice by parliamentarians, health experts and commentators.

3. **Resources commensurate to the mandate:** The OPO would need to be given the resources required to deliver the agreed mandate. As there is already a large range of information about patient outcomes, the marginal resources needed by the OPO are nevertheless likely to be fairly small. On the analogy of the OBR, its annual budget is £1.75m, which is a tiny amount in the wider context of the health budget.

4. **Full access to information:** This is critical to the success of the OBR. HM Treasury, HM Revenue and Customs and the Department for Work and Pensions share their plans and forecasts with the OBR, which frequently asks for more information or detail. Data on patient outcomes is dispersed across the health and care system, so access would be vital to the success of the OPO too.

5. **Transparency:** The OBR has built its reputation – and succeeds in improving accountability – in large part because it is transparent about how it arrives at its judgements and what conversations have taken place with the suppliers of information in advance. The health bodies described as operating in Canada and Australia demonstrate a similar commitment to transparency.

6. **Effective communications channels:** Due to the high level of public interest in the work of the OBR – and this would undoubtedly be true of the OPO too – effective communications are vital. This means publishing clear and concise material; and having a leader who is a confident and articulate speaker for news media as well as more expert audiences.

7. **External evaluation of its work:** The OBR is subject to periodic external evaluation, as well as to scrutiny by Parliament and its Committees. In addition to these forms of evaluation, the OPO would also need to be responsive to patient voice. There are a number of options for achieving this, e.g. via the membership of the body and its supervisory board; consultation on the mandate before it is set.

**Examples of what the Office for Patient Outcomes could achieve**

*Ensuring a positive experience of care*
This is a major focus area for the health and care system. Patients and their families prioritise it, as do professionals. Public concern about the experience of care has risen though, due for example to the issues raised by the Mid Staffordshire NHS Foundation Trust Public Inquiry.

At present the CQC, for example, carries out an annual inpatient survey. There are other sources of information too and, as already noted in this paper, co-ordination between them is poor. The information disseminated by the HSCIC is relatively technical in nature; and unlikely to be used confidently by patients or their families. CQC data on GP surgeries is more accessible but Britain Thinks research suggests that patient awareness is extremely low.

The advantages of the OPO in relation to this area of patient outcomes would therefore be to:

- Create a single, authoritative source of information;
- Boost the salience of that single source for patients and their families through high profile reports to Parliament which will be picked up by the media too; and,
- Increase significantly the role of patient voice in deciding what information is collected and published.

Cancer outcomes

These are plainly an issue of high public concern. UK cancer outcomes have been improving though lag behind many of our peer countries. HSCIC data is very detailed but technical in nature and very few patients or families are likely to be in a position to use it. Analysts and parliamentarians need to spend time working with it carefully if they are to deploy it in improving accountability too. The role of patient voice in deciding what data is readily available, or how it is presented, is very limited.

Cancer Research UK, by contrast, produces much more accessible information about the incidence of cancer and survival rates. It is well sourced and available online without the need to download large documents. While it bears the authority of a major medical research charity, nevertheless it isn’t official data and that may limit its use in improving accountability.

Equally, making comparisons between the UK and peer countries requires any potential user of the data to also look elsewhere.

The advantages of the OPO in relation to cancer outcomes would therefore be to:

- Increase the role of patient voice in deciding what data is available and how it is presented;
- Create a single authoritative source of information about cancer outcomes which can be confidently used to sharpen accountability for improvement; and,
- Simplify radically the task of comparison between the UK and peer countries for any user.

Next steps

This paper is written as a proof of concept for the OPO. We argue that there are substantial problems with current information about patient outcomes; similar problems were faced in the
area of public finances and have been successfully tackled by the creation of the OBR; and the key principles underlying the OBR are replicable in the health and care system under a body like the OPO.

Creating and providing to the public better information about patient outcomes is clearly a priority for the Government at this time. Enhancing the role of patient voice in the health and care system also runs as a theme through many current initiatives, including the Accelerated Access Review. For these reasons, and given the precedent of the OBR, we argue that the OPO is consistent with the direction of Government policy.

Clearly designing the OPO would need more consideration of issues touched on, but developed only lightly, in this paper. For instance, the remit for the OPO would as a practical matter have to select some priority areas where the OPO should focus first in terms of pulling together a suite of data about patient outcomes. The successful operation of the OPO would also depend on a strong set of working relationships with other health bodies – primarily the HSCIC and CGC. The same is true of the OBR and, on its creation, a protocol was quickly written to govern the relationships between it and HM Treasury, HMRC and DWP.

That said, it is likely that many of the problems with current information about patient outcomes – summarised in this paper – can also be addressed by other institutional innovation. For instance, reform of the HSCIC could transform it into something very much like the OPO envisaged by this paper. Equally, if the CGC has broad support in the role it discharges, then that role could be enhanced on the lines described here.

In the end, this paper is not making the case for another body, for the sake of having another body, or because the existing bodies in the health and care system are functioning poorly, but rather because there are substantial issues with current information about patient outcomes that should be addressed to sharpen accountability and improve the responsiveness of the health and care system. Doing so is the key objective; and the OPO is suggested as one possible means to that end.