

## MYTH 2

**OUTCOMES  
ARE TOO DIFFICULT  
TO MEASURE**

THE FOUR MYTHS 2 / 4



#outcomesmyths

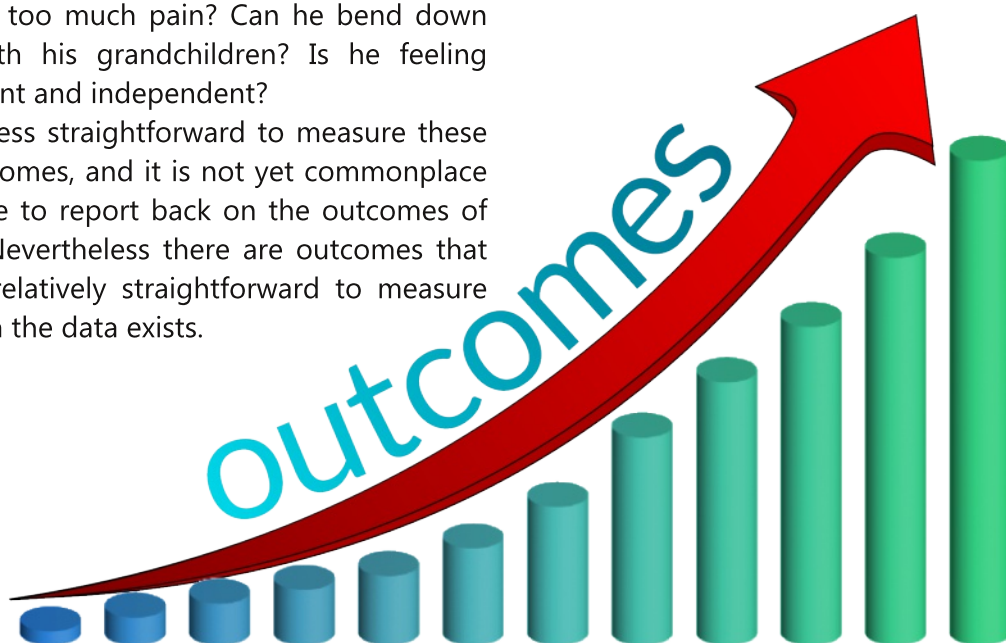
**D**efining outcomes is one thing; measuring them is another. This is often where people tell us they encounter what seem like dead ends. All too often, they are told that the data needed to measure outcomes doesn't exist or that outcomes simply cannot be measured. They are also told that data collection is already too much of a burden in the cash-strapped NHS.

It is relatively easy to count activity and outputs – like the number of knee replacement operations undertaken, the number of post-operative infections or number of physiotherapy sessions delivered – and these data are easily accessible. This is what the NHS does really well. **But as important as these are, they don't really tell us whether these things that have been done to people have done them any good** – is the person who had the knee replacement able to walk without too much pain? Can he bend down and play with his grandchildren? Is he feeling more confident and independent?

True, it is less straightforward to measure these kinds of outcomes, and it is not yet commonplace to ask people to report back on the outcomes of their care. Nevertheless there are outcomes that are already relatively straightforward to measure and for which the data exists.

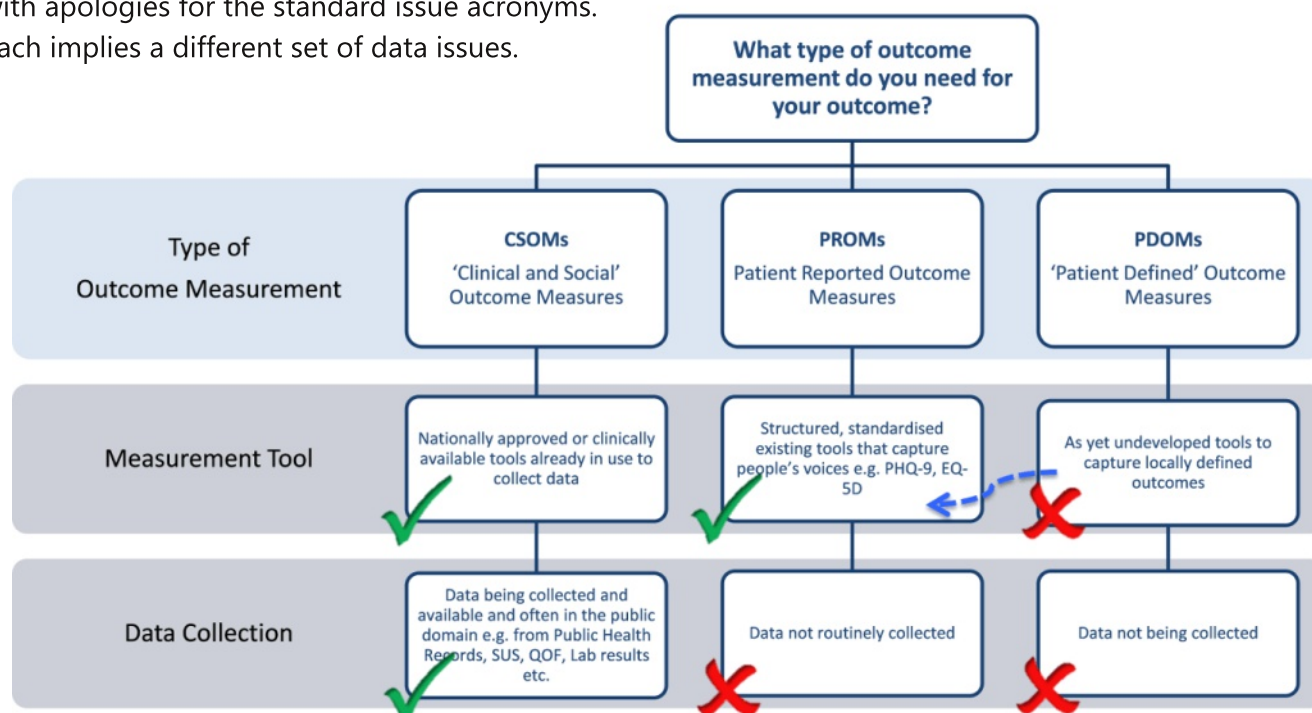
Outcomes measurement is a challenging topic, but at OBH we have learnt that:

- A great deal of the data collected in the NHS is designed to help measure inputs, processes and outputs – but, with care, it can often also be used to measure outcomes
- For a typical patient segment, data exists which allows 50% to 60% of outcomes to be measured – and this may be a good enough start. The rest may require additional data collection, often asking people to report back on their outcomes
- We have yet to come across any satisfactory technical reason why outcomes can't be measured



## DIFFERENT TYPES OF OUTCOMES HAVE DIFFERENT MEASUREMENT CHALLENGES

We work with three types of measures – with apologies for the standard issue acronyms. Each implies a different set of data issues.



### CSOMs - 'Clinical and Social' Outcome Measures

Clinical Outcome Measures are objective measures relating to health and quality of life, such as the physical or psychological aspects of disease, symptom control, complications, the avoidance of adverse effects and the speed of recovery, including the impact on quality of life.

Social Outcome Measures relate more to someone's life situation, such as housing, education and employment, which may be affected by their health condition.

Data useful for measuring clinical and social outcomes is often already collected and available via nationally approved or clinically available tools. Key datasets (all administered by HSCIC<sup>7</sup>) include, Hospital Episode Statistics (HES); a wide range of clinical audits; Quality Outcomes Framework (QOF); Adult Social Care Outcomes Framework (ASCOF); and the NHS Safety Thermometer. Another key source is the Office of National Statistics<sup>8</sup> for public health records.

“

*The relevance of social outcomes is clear, when you think about child health. If families and children are having to attend multiple hospital appointments, educational attainment and the impact on employment status of days off work become important outcome measures.*

**Nabiha Sachedina – policy expert, NHS paediatrician, MBA and MPP**

”

<sup>7</sup> HSCIC: [www.hscic.gov.uk](http://www.hscic.gov.uk) (HES: [www.hscic.gov.uk/hes](http://www.hscic.gov.uk/hes), Clinical Audits [www.hscic.gov.uk/clinicalaudits](http://www.hscic.gov.uk/clinicalaudits), QOF: [www.hscic.gov.uk/qof](http://www.hscic.gov.uk/qof), ASCOF: [www.hscic.gov.uk/ascof](http://www.hscic.gov.uk/ascof), NHS Safety thermometer: [www.hscic.gov.uk/thermometer](http://www.hscic.gov.uk/thermometer))

<sup>8</sup> ONS <http://www.statistics.gov.uk/hub/health-social-care>

## PROMs - Patient Reported Outcome Measures

A number of **structured, standardised and validated tools exist** to capture people's own reports on their outcomes – as distinct from their experiences of care or their levels of satisfaction. These have been found to be useful not only for measurement purposes but as an improvement tool in their own right too<sup>9</sup>. The general direction at a policy level is for **routine and systematic collection of PROMs** in the line of care, as outlined in the NHS Mandate 2014/15<sup>10</sup>.

'**Generic**' tools in common use include: EQ-5D<sup>11</sup>, SF-36<sup>12</sup>. These enable valid comparison across large populations of people with different conditions, but they are inevitably less specific, making it difficult to draw firm conclusions for specific groups of people with similar health needs.

**Condition-specific PROMs** are, as the name suggests, more sensitive to the details of that condition. Good examples include:

- The Oxford Hip Score<sup>13</sup>
- Audit of Diabetes Dependent Quality of Life – ADDQoL<sup>14</sup>, PHQ9<sup>15</sup>
- Hospital Anxiety and Depression Scale (HADS)<sup>16</sup>

The national PROMs programme<sup>17</sup> measures health gain in patients undergoing hip replacement, knee replacement, varicose vein and groin hernia surgery in England, based on responses to questionnaires before and after surgery. However, it is focused on specific procedures rather than conditions or discrete population segments.

## PDOMs - 'Patient Defined' Outcome Measures

In OBH's experience, exploring outcomes that matter with people and clinicians always results in a few outcomes for which neither clinical data nor

existing PROMs are available – we call these PDOMs. This is the time to think carefully about whether and how to go about gathering new data.

There are lots of things to consider:

- **how to involve people** with the condition in survey design, as recommended by ICHOM<sup>18</sup>
- whether to aim for a **census-based survey** as recommended by Press Ganey<sup>19</sup>, or a **representative sample-based survey**, and if so, how large a sample will be needed
- **when and how often to survey** – at specific interactions with the health service, e.g. post-operative and/or at fixed or rolling monthly/quarterly/annual intervals. There are advantages to making data collection a natural part of the care process, e.g. asking people to complete forms while waiting for an appointment
- **what media to use** – smartphone app, paper survey, online form
- **how to validate data** at each stage of the process
- **the resources required** to distribute the survey, capture data and analyse results

<sup>9</sup> Patient reported outcome measures could help transform healthcare, Black (2013) <http://www.bmj.com/content/346/bmj.f167>

<sup>10</sup> NHS Mandate 2014/15, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/256406/Mandate\\_14\\_15.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256406/Mandate_14_15.pdf)

<sup>11</sup> Using the EQ-5D as a performance measurement tool in the NHS, Devlin et al (2009) <http://openaccess.city.ac.uk/1502/>

<sup>12</sup> SF-36, 36-Item Short Form Survey from the RAND Medical Outcomes Study, [http://www.rand.org/health/surveys\\_tools/mos/mos\\_core\\_36item.html](http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html)

<sup>13</sup> Oxford Hip Score, Patient Reported Outcomes Measures from the University of Oxford, <http://www.isis-innovation.com/outcomes/orthopaedic/ohs.html>

<sup>14</sup> Audit of Diabetes Dependent Quality of Life, Patient- Reported Outcome Measurement Group, Oxford A Structured Review Of Patient- Reported Outcome Measures (PROMs) For Diabetes (2009) [http://phi.uhce.ox.ac.uk/pdf/Diabetes\\_2009FINAL.pdf](http://phi.uhce.ox.ac.uk/pdf/Diabetes_2009FINAL.pdf)

<sup>15</sup> Patient Health Questionnaire, PHQ9, <http://www.patient.co.uk/doctor/patient-health-questionnaire-phq-9>

<sup>16</sup> Hospital Anxiety Depression Scale, Patient- Reported Outcome Measurement Group, Oxford An Overview Of Patient-Reported Outcome Measures For People With Anxiety And Depression 2009, [Http://Phi.Uhce.Ox.Ac.Uk/Pdf/Depression%20and%20anxiety%20promgroup%20oxford%20may2010.Pdf](http://phi.uhce.ox.ac.uk/Pdf/Depression%20and%20anxiety%20promgroup%20oxford%20may2010.Pdf)

<sup>17</sup> National PROMs Programme, [www.hscic.gov.uk/proms](http://www.hscic.gov.uk/proms)

<sup>18</sup> ICHOM, [www.ichom.org](http://www.ichom.org)

<sup>19</sup> Press Ganey, Patient Voice – census-based surveying, <http://www.pressganey.com/ourSolutions/patient-voice/census-based-surveying.aspx>

## BUT WHAT ABOUT THE DATA COLLECTION BURDEN?

In an ideal world, **data collection would not be a burden**. In an ideal world, the right sort of technology in the right place that links up securely to the right systems would make data collection and outcomes measurement far easier. At the moment, **joining the dots takes time and is a key focus of OBH's work**.

Our experience is that a huge amount of the data that is collected in the NHS tends to be of limited value or is not used in meaningful ways –

and that doesn't just apply to data required by national bodies. Often it would be more useful if pockets of data in different parts of the system were linked up, and if information governance practices were better aligned. In other cases, there is a degree of wasted effort going on – resource that could be redirected to collecting the kind of data needed to better measure outcomes.

## PRAGMATISM IS KEY

It is almost never the case that the perfect data is available for measuring any given outcome to begin with. For example:

- **data is not always accessible:** blindness is a potential outcome to avoid for someone with diabetes, but population level data about the prevalence of blindness in diabetes, from the electronic certificate of vision impairment, is not yet accessible. So instead, we have used the NHS Diabetic Eye Screening programme, to find data about the prevalence of severe retinopathy treatment in people with diabetes.
- **data is sometimes fragmented:** taking another example of a possible outcome for diabetes, erectile dysfunction is not recorded well in hospital episode statistics, but may be available in GP data

- **the data that is available may not quite match up to what is needed:** while the 'segment' targeted is perhaps older people living with frailty over the age of 75, available data may relate to older people over the age of 65 and you need to explore whether it is possible to take a 'cut' of the data for the relevant age cohort and the definition of frailty that has been identified
- **data may not be available as frequently** as you would like and often there may be a delay in getting the data, sometimes more than a year

Nevertheless, neither **the NHS nor social care is short on data and plenty of it is useable**. Choices have to be made on whether available data is 'good enough for now', or whether additional data collection is warranted.



*Measuring outcomes systematically is a journey not a destination. The first step in developing any successful outcomes measurement system is to start somewhere. It means getting all the right people around the table and agreeing to be deeply pragmatic. Is it worth the effort? How else will we know if the care we are providing is doing any good?*

**Dr Rupert Dunbar-Rees, Founder, Outcomes Based Healthcare**





## King's Health Partners' Outcomes Books

King's Health Partners (KHP) is committed to providing **accurate and timely information about patient care**, and believes that **identifying, measuring and publishing healthcare outcomes results in a culture of improvement and increased value**.

Every one of KHP's twenty one Clinical Academic

Groups are working towards producing 'outcomes books'<sup>20</sup> for their specialties. These provide contextual narrative and data across a range of outcomes, benchmarked wherever possible. They are aimed at both clinical and public audiences, and will be updated annually. They are underpinned by more detailed data which allow clinicians to discuss and compare performance down to ward level.

**Professor John Moxham, Director of Clinical Strategy at KHP**, is spearheading this initiative:

*"Measuring outcomes is difficult. My advice always is that you have to be pragmatic and start somewhere: use the data that already exists and get people talking. It is those conversations – between clinicians and with patients – that really drive improvements.*

*It is harder in some clinical areas than others, but we regard it as an ongoing process and a permanent change in the way we do things. We may even publish some outcomes books that are*

*incomplete, because we know we will get there over time.*

*Continuing to enrich the data available to measure and compare outcomes is an essential component of our strategy. We are in the process of linking up information systems between our trusts – and beyond them to our local GPs. Working with our partners on the Health and Wellbeing Board, this will enable us to track outcomes for people across full cycles of care not just within the hospitals but out into primary care and beyond."*

## TACKLING THE DATA DETAIL - OBH AND NORTH CENTRAL LONDON CCGS

Having worked on **defining the outcomes that matter to older people** living with frailty, people with diabetes and people with mental health, OBH continues to work with Camden, Islington, Barnet, Haringey and Enfield CCGs.

The next step involves detailed work to **create the right data architecture** for each one – in other words, figuring out what data is needed to measure it, as well as whether it exists and can be accessed.

For each type of outcome (CSOM, PROM and PDOM) and each population segment, we work with **Expert Reference Groups** (ERGs) to seek a range of views and insights on potential measures and to test their practicality.

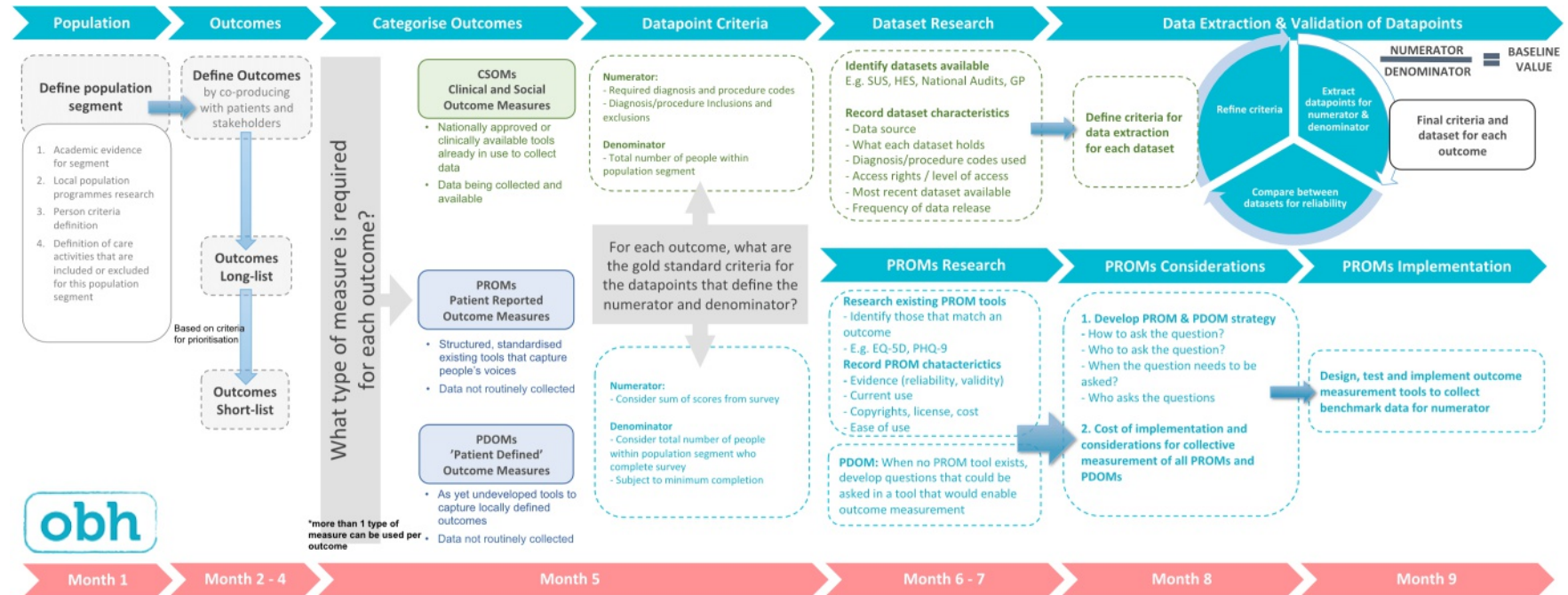
OBH has put together a process map to summarise the process for creating the data architecture

Creating a data architecture means addressing a series of questions:

- What data would be needed to measure this outcome?
- Is that data available – or is there a good enough proxy? If so, which dataset and who holds it?
- What exactly does that dataset cover? Who and what is included and excluded?
- How often is the data collected and what is the delay before it becomes available?
- What permissions are required to access the dataset?
- Are there any other constraints or issues with the dataset?
- What is the detailed technical measure we need? What numerator and denominator is appropriate?
- What is the most appropriate baseline position to use so that progress over time can be measured?

<sup>20</sup> King's Health Partners, <http://www.kingshealthpartners.org/flipbooks/medicine/>

# Outcomes Measurement Process Map



This can be painstaking work – but it is **essential upfront activity** when the aim is to measure whether the care being provided is making a positive difference to people's lives. The work in North Central London is ongoing – the key has been to get the right knowledge and expertise in the room, particularly public health and informatics experts, and to be open to adopting the solutions others have found. To pick out just a few examples:

- **The National Diabetes Audit**<sup>21</sup> will be invaluable in measuring some of the clinical diabetes outcomes. There is some timelag to deal with, but it is possible to take bespoke cuts of the data to match specific outcomes requirements
- **The NHS Safety Thermometer**<sup>22</sup> contains a useful indicator on falls within 72 hours of leaving a care setting, which matches a key

outcome for older people living with frailty

- **The Adult Social Care Survey**<sup>23</sup> contains a good outcome indicator for the same group: older people still at home 91 days post-discharge. While that indicator relates to the over-65 age group, it should be possible to extract data relating to the over-75 age group
- **In some cases, choices need to be made:** whether to use a clinical measure for symptom control albeit with shortcomings on its completeness (e.g. A&E admission for Diabetic Ketoacidosis (DKA)) or whether to use a PROM which asks patients to report on how well they feel they are able to control their symptoms

The result of this work will be a **clearly articulated description of the outcomes required**, and how they can be **measured, which can be incorporated into a contract** in which all parties have confidence.



*"It's a process of exploring the best fit between available data and the outcome you want to measure, until you get something that both commissioners and providers are comfortable with."*

**Alisha Davies, Acting Consultant in Public Health at Haringey Council**



## **"IF WE DEFINE AND MEASURE OUR OWN OUTCOMES, WE CAN'T BENCHMARK AGAINST OTHERS"**

This is true – to some extent – but it's a poor reason not to begin measuring outcomes. **Outcomes-based commissioning is in its infancy.** The more localities develop outcomes frameworks and the more standard frameworks are developed at national and international level, the more **benchmarking will become possible.** You could also argue that:

- Useful local, national and international benchmarks do exist for a number of outcomes – from mortality rates to complications of diabetes to a number of generic PROMs
- Benchmarking your own performance over time

is really valuable and a good place to start regardless

- There is value in locally defined outcomes that have limited applicability elsewhere – that is where PDOMs come in. For example, in one area it might be very significant that people are able to bend down to pray post-knee surgery but for another the most important outcome is the ability to drive as they live in a remote area with few transport links
- Collaborating with local CCGs or others with similar populations is worth exploring for benchmarking purposes – OBH is working with five CCGs in London to do exactly this.

<sup>21</sup> National Diabetes Audit UK, [www.hscic.gov.uk/nda](http://www.hscic.gov.uk/nda)

<sup>22</sup> NHS Safety Thermometer, [www.hscic.gov.uk/thermometer](http://www.hscic.gov.uk/thermometer)

<sup>23</sup> Adult Social Care Survey, <http://www.hscic.gov.uk/catalogue/PUB10284/meas-adul-soci-care-fwrk-fin-eng-11-12-rep.pdf>



*"Measuring outcomes is not that hard: the important thing is to make sure you have intelligent conversations about what the data does and doesn't show."*

**Dr Tim Williams, Co-founder, myClinicalOutcomes**



## READING LIST

- Every one of King's Health Partners' twenty-one Clinical Academic Groups are working towards producing 'outcomes books'<sup>24</sup> for their specialties. King's Health Partners is the Academic Health Science Centre that brings together King's College and three NHS Foundation Trusts: King's College Hospital, Guys and St Thomas' and South London and Maudsley.
- Professor Michael E. Porter: a supplement on measuring outcomes<sup>25</sup>, to his seminal paper What is Value in Healthcare?<sup>26</sup>
- Getting the most out of PROMs<sup>27</sup>, a 2010 report from The King's Fund provides a great overview of PROMs. Nick Black also looks at the potential of PROMs to transform healthcare in his 2013 BMJ article<sup>28</sup>.
- The PROM group in the Nuffield Department of Population Health at the University of Oxford<sup>29</sup> provides a near comprehensive resource, including work on patient reported measures relating to integrated care.

<sup>24</sup> King's Health Partners, Outcomes books, <http://www.kingshealthpartners.org/info/outcomes-books>

<sup>25</sup> Supplementary Appendix 2 to: Porter ME. What is value in health care? N Engl J Med 2010;363:2477-81. DOI: 10.1056/NEJMp1011024

<sup>26</sup> What is Value in Healthcare? Porter (2010) <http://www.nejm.org/doi/full/10.1056/NEJMp1011024>

<sup>27</sup> Getting the most out of PROMS, Putting health outcomes at the heart of NHS decision-making, Devlin & Appleby (2010), <http://www.kingsfund.org.uk/sites/files/kf/Getting-the-most-out-of-PROMs-Nancy-Devlin-John-Appleby-Kings-Fund-March-2010.pdf>

<sup>28</sup> Patient reported outcome measures could help transform healthcare, Black (2013), <http://www.bmj.com/content/346/bmj.f167>

<sup>29</sup> PROM Group, University of Oxford, <http://phi.uhce.ox.ac.uk/home.php>