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**THE SOUTH AFRICAN CHAPTER OF THE INTERNATIONAL SOCIETY FOR
PHARMACOECONOMICS AND OUTCOMES RESEARCH SUBMISSION TO THE HEALTH
MARKET INQUIRY (HMI)**

IN RESPECT OF THE DISCUSSION DOCUMENT:

*'Health outcome measurement and reporting: Improving the cost and effectiveness of clinical care
in a competitive private healthcare sector in South Africa'*

Date: 21 September 2017

1. Introduction

The South African Chapter for Pharmacoeconomics and Outcome Research is deeply gratified by the announcement by the Health Market Inquiry that it has recognized measurement and reporting of health outcomes as a important area for improvement in the South African healthcare system.

We apologise for the submission from ISPOR missing the deadline – but unfortunately timelines were very short for a multi-disciplinary NGO to respond. In addition, our annual Conference was held on 19 and 20 September and we needed to take inputs from our membership.

The Objectives of ISPOR South Africa are to:

- Provide an environment where researchers, healthcare practitioners and decision-makers interested in pharmacoeconomics and outcomes research can share knowledge at a national and international level.
- Serve as a neutral forum bringing together researchers, healthcare practitioners and decision-makers interested in pharmacoeconomics and members of the pharmaceutical industry, health-related organizations, public health and academia.
- Act as a facilitator at a local level for individuals interested in pharmacoeconomics and outcomes research.
- Provide the opportunity for local chapter members to become familiar with the activities of ISPOR International as well as participate in its activities.
- Endorse training and education programmes in pharmacoeconomics and outcomes research.
- Promote local development and monitor implementation of guidelines in pharmacoeconomics and outcomes research.

ISPOR GLOBALLY

ISPOR SA is a local chapter of the ISPOR International organization.

Globally, ISPOR has been in existence for twenty years and currently has a membership of over 9 500 individuals from 114 countries.

ISPOR exists to foster excellence in the science of pharmacoeconomics and health outcomes research and its use in health care decisions.

Mission: The mission of ISPOR is to increase the efficiency, effectiveness, and fairness of health care to improve health.

Vision: ISPOR is recognized globally as the authority for outcomes research and its use in health care decisions towards improved health.

Scope: The ISPOR scope and sphere of influence includes outcomes researchers, health technology developers and assessors, regulators, health economists, health care policy makers, payers, providers, patients, populations, and society as a whole.

2. ISPOR South Africa Comments on the discussion document

2.1 ISPOR SA is in full support of improvement of health outcome reporting and measurement, which underpins value based and patient centred health care delivery.

The call for proper **outcome** measurement in South Africa is not a new idea introduced by the HMI discussion document in question. The White Paper for National Health Insurance (NHI) for South Africa, which the Government published on 11 December 2015, contained the intention to measure outcomes and link them to provider performance:

“Outcomes will be measured and monitored through a performance management framework and will be in accordance with agreed upon performance standards. Eventually performance management will cover public health outcomes in a specified catchment population...” (Paragraph 77 of NHI White Paper)

ISPOR SA has addressed the issues of real-world data analysis and outcomes research in our conferences held since 2007, which have afforded us the opportunity to highlight and understand the challenges and opportunities presented by large claims databases and registries locally which collect information on patient outcomes.

Collectively we are aware of multiple initiatives to measure process, structure and health outcomes as part of quality improvement initiatives throughout the country.

ISPOR SA does feel that the system would benefit from improved coordination, public reporting and collective contributions of databases to the initiative.

In addition, our local members participate in the ISPOR International processes, which include:

- Good research practice task forces
- Special interest groups
- Development of guidelines for outcomes research and real-world data analysis

2.2 ISPOR SA has concerns about the confusion of terminologies used in the MHI document and the potential for this process and the proposed outcomes monitoring body to duplicate work already being undertaken at several other levels

The HMI paper mentions the importance of quality as a guiding factor for patients to select health services as well as *“A general framework defining the nature of desired outcomes, for the healthcare consumer in South Africa, needs to be developed, as a first step in the process of providing the South African private healthcare system with relevant and comparative information on quality related outcomes”*.

ISPOR urges the HMI to recognize that health outcomes and health quality are not the same thing.

The Donabedian model is a conceptual model that provides a framework for examining health services and evaluating quality of health care. According to the model, information about quality of care can be drawn from three categories: “structure,” “process,” and “outcomes.”¹

Thus, while outcomes are a key component of the quality of care of a system, structure and process indicators are also important.

ISPOR SA is thus concerned that the HMI might find itself duplicating work undertaken by the Office of Health Standards Compliance, and the Lancet Commission on high Quality health systems which was recently launched in the country (May 2017).

¹ Donabedian, A. The Quality of Care: How can it be assessed? JAMA 1988;260(12):1743-1748

2.3 Patient Registries can present many opportunities for data collection, but can also be costly to operate and require incentive for provider and patient participation

At a recent session of the International Society for Pharmacoeconomics and Outcomes Research, the following has emerged from countries attempting outcomes measurement is the following (ISPOR Plenary Session, ISPOR European Conference 2015)²:

- The costs and resource requirements for registries and outcomes measurement has meant that it has largely been confined to specific diseases or technologies.
- A good deal of work on the topic has been done in theory – but countries are still trying to implement in practice
- Estimations from studies performed on registries in Australia in 2015 estimated that each registry cost \$ 1 million (R15 million) per annum to run – and the time taken from setting up registries and actually managing to get decent useful data from these is several years. In many cases technology has moved on.
- On the whole systems are yet to be able to identify the cost-benefit ratios of running such registries

Using Australia as an example. the number of known clinical registries has risen from 28 in 2006–2007 to 37 in 2012, few of which had national coverage. It was also unclear how many of these provide feedback on quality of care³.

Despite some evidence of the capacity of registries to improve health outcomes, several challenges have been identified which have impacted the development of registries.

- Establishing a new registry requires a considerable long-term commitment of resources, which is often difficult to garner⁴.
- Information required by registries is often not routinely collected in a standardised manner at a population level. This is particularly the case in developing countries, where even establishing cancer incidence registries is challenged because of low priority in resource allocation.

² ISPOR International : <https://www.ispor.org/Event/ReleasedPresentations/2015Milan>

³ Measurements for improved quality in health care in Australia by Swedish Agency for Growth Policy Analysis. http://www.tillvaxtanalys.se/download/18.5f097bc113eacc3d6d5133/1369032981940/direct_response_2013_05.pdf.

⁴ Solomon DJ, Henry RC, Hogan JG et al. Evaluation and implementation of public health registries. Public Health Rep 1991;106:142–50.

- It is not possible to evaluate the direct impact of a registry on the cost or quality of healthcare until it achieves a sustainable operation, which can take considerable time.

Only a few studies have quantified the value of establishing clinical registries in terms of economic and clinical impact; hence, supporting evidence for costly investment in the registry is minimal⁵.

In South Africa, several patient registries have been running for some time. The consensus between ISPOR SA members at the recent ISPOR SA Conference was:

- It is possible to run registries at an affordable cost, but it is likely that this will limit the country to a few disease areas only.
- Given the number of questions which can be posed, registries need to be set up to answer specific questions to ensure that the correct data is collected and analysed.
- Providers do not easily participate in the additional workload required by registries unless there is some incentive to do so. This need not be monetary – where patient access to treatment has been determined through participation in the registry process, this has worked well in the past.

2.4 Claims data for Outcomes Research

Although medical schemes claims data seems a good source to draw clinical outcomes from, there are still significant challenges inherent in doing this.

These are well spelt out in a Rand Corporation document examining similar issues in the United States, where large claims databases are also examined⁶:

- Claims data from different insurances may take very different formats and may not be easily accessible or analysable for researchers outside of the organization
- Different sets of information may be captured and coding may not be uniform
- Coding can also be fundamentally inaccurate – both codes submitted and codes processed
- Coding can also be inappropriate or incomplete a challenge to analysis

⁵ Han W, Sharman R, Heider A et al. Impact of electronic diabetes registry ‘Meaningful Use’ on quality of care and hospital utilization. *J Am Med Inform Assoc* 2016;23:242–7

⁶ Rand Corporation. CONCEPTUALIZING AND MEASURING QUALITY OF CARE.
https://www.rand.org/content/dam/rand/pubs/rgs_dissertations/RGSD171/RGSD171.ch2.pdf

- Reimbursement policies may also have a very fundamental impact on patient and provider behaviour which cannot be adequately capture through claims data.

All of these concerns apply in the South African private insurance environment. In our session at our recent conference on “Real-World Evidence” (Tuesday 19 September) these were all highlighted as concerns to do with claims database extraction and analysis.

Many challenges remain in using current claims data to extract outcomes information, and in most cases, intermediate and process outcomes are still the major indicators which institutions are able to analyse.

2.5 Comments regarding the proposed independent statutory body

ISPOR SA believes this may be a premature step, and that obtaining funding for this initiative will be difficult.

- a) Such a body is at risk of **redundancy**. The spelled out mandate of the OHSC already has some overlaps with the envisaged functions of the intended independent body⁷.
- b) The body could demand enormous financial and human resources from the already under-resource national reserve.

3 Recommendations

ISPOR SA believes there is much to be learned from our counterparts attempting outcomes research in other countries in the world, as well as from local initiatives in the country, before we embark on a process to implement legislation and another large statutory body for quality purposes.

We are pleased to see that the MHI is embarking on a consultation process as indicated by the announcement to hold the “Health Outcome Measurement and Reporting Seminar” on 22 September.

We believe that the private sector should invest in some key pilots projects ahead of a substantive move to start collection of outcomes data nationally.

⁷ OHSC website. <http://ohsc.org.za/index.php/who-we-are/mandate>



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ISPOR would also like to take this opportunity to offer our services to the HMI from our wide global network of outcomes measurement experts.

Substantive training material, conceptual frameworks and discussion papers are available from ISPOR International www.ispor.org.

4 Conclusion

ISPOR SA appreciates the opportunity to engage in this process and hopes that the country will be able to benefit from the knowledge and experience of the local chapter and the international collective in these issues.

Best Regards

A handwritten signature in black ink that reads "Lynda Woods". The signature is written in a cursive, flowing style.

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