ICHOM

International Consortium for Health Outcomes Measurement
Newsletter April 2015

Dear ICHOM friends,

I hope this finds you and yours well. Already, 2015 has been a productive year for the ICHOM team. As we look ahead, it's my pleasure to update you on our work: where we stand today and where we plan to be in one year's time. I encourage you to review this edition of our newsletter, to distribute it within your networks, and to visit us at www.ichom.org for regular updates. I also encourage you to follow us on Twitter (@ICHOM_ORG) for the latest news in outcomes measurement and value-based health care.

In 2014, our standardization work continued apace. Guided by our teams in Cambridge and London, our expert Working Groups developed Standard Sets for eight of the world's most burdensome medical conditions, bringing the number of our completed Standard Sets to twelve. By the end of this year, we aim to bring that total to 20. I invite you to scroll down for more information, and to review our revamped Reference Guides, which are now available on our website.

We also made substantial headway in implementation: supporting providers as they begin to measure one or more of the Standard Sets. We launched the Implementation Network, as well as the Certified Suppliers program. ICHOM Certified Suppliers are IT providers that are integrating the Standard Sets into their data-collection platforms in order to facilitate reliable, secure measurement. I encourage you to learn more about the Certified Suppliers by clicking here.

We ended 2014 with our international conference at Harvard Business School. As many of you know, attendees numbered nearly 500 and represented 28 countries. Since then, the response has been overwhelming. Providers from across the globe have reached out to express their enthusiasm for our work and their interest in measuring one or more of the Standard Sets. Payers, suppliers, and others have similarly demonstrated their desire to push forward the value agenda.

In the coming months, we will share with you the details of our next conference. In the meantime, I am pleased to make an exciting announcement. In recognition of our growing list of partners in Europe and elsewhere around the world, the Fourth ICHOM Conference will take place in the spring of 2016 in London. I look forward to apprising you of more information later in the year, and I hope that you will be able to join us for this important event.

My colleagues and I are grateful for a successful 2014 and for a productive first quarter of 2015. On behalf of our team, thank you for your support. We look forward to advancing our relationship with each of you, and with the organizations you represent.

Best regards,

Christina R. Åkerman
ICHOM President

CHRISTINA R. ÅKERMAN

IN 2014, OUR STANDARDIZATION WORK CONTINUED APACE. ICHOM'S COMPLETED STANDARD SETS NOW COVER OVER ONE-THIRD OF THE GLOBAL DISEASE BURDEN. WE HAVE ALSO MADE SUBSTANTIAL HEADWAY IN IMPLEMENTATION: SUPPORTING PROVIDERS AS THEY INTEGRATE ONE OR MORE OF THE STANDARD SETS INTO THEIR PRACTICES.

STANDARDIZATION UPDATE

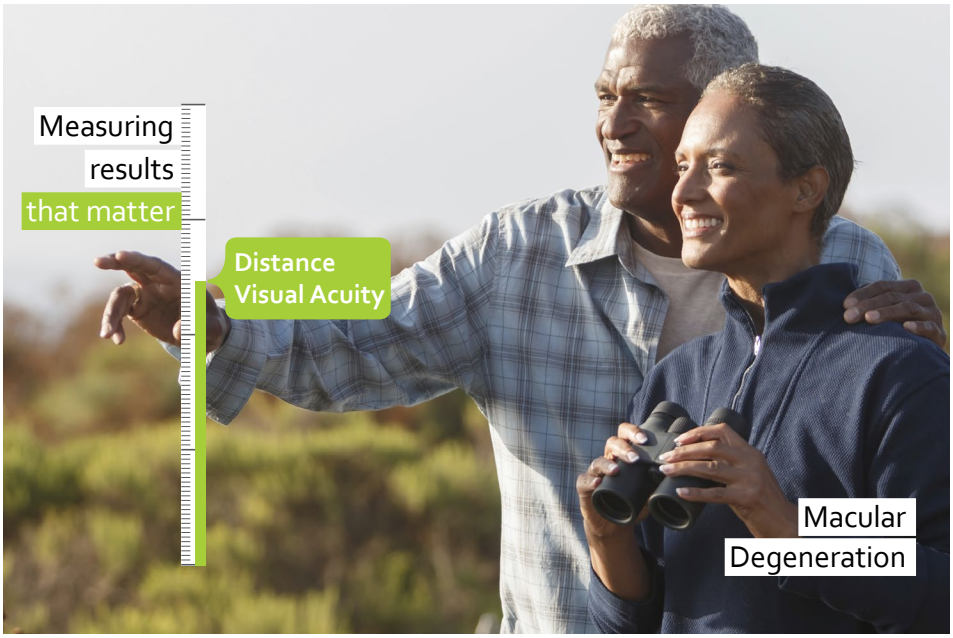
New Standard Sets, revamped Reference Guides

ICHOM STANDARD SETS

2013
- CORONARY ARTERY DISEASE
- CATARACTS
- LOCALIZED PROSTATE CANCER
- LOW BACK PAIN

2014
- PARKINSON'S DISEASE
- CLEFT LIP & PALATE
- DEPRESSION & ANXIETY
- ADVANCED PROSTATE CANCER
- LUNG CANCER
- MACULAR DEGENERATION
- STROKE

Expected 2015
- DEMENTIA
- HEART FAILURE
- INFLAMMATORY BOWEL DISEASE
- FRAIL ELDERLY
- BRAIN TUMORS
- BREAST CANCER
- COLON CANCER
- PREGNANCY AND CHILDBIRTH



In 2014, our standardization team and expert Working Groups developed Standard Sets for eight medical conditions, bringing the number of completed Standard Sets to twelve. ICHOM Standard Sets now cover fully 35-percent of the global burden of disease (GBD). By 2017, we aim to cover more than half.

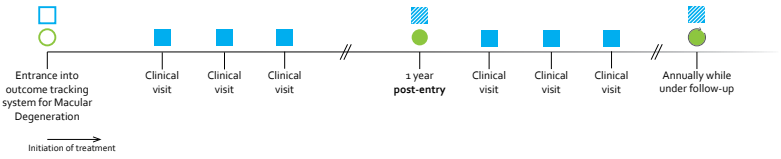
Last year, we expanded the reach of our Standard Sets to include cerebrovascular conditions, congenital anomalies, mental disorders, and nervous system diseases. This year, among our priority conditions are brain tumors, breast cancer, colon cancer, dementia, frail elderly, heart failure, and pregnancy and childbirth.

In addition to our standardization efforts, we have worked closely with pilot implementers around the world to revamp our Reference Guides. Every Standard Set is supplemented by a Reference Guide that explains the content of the Standard Set and provides the detailed information needed to implement it in a globally standardized way. **For completed Standard Sets, revised Reference Guides are now available on** www.ichom.org.

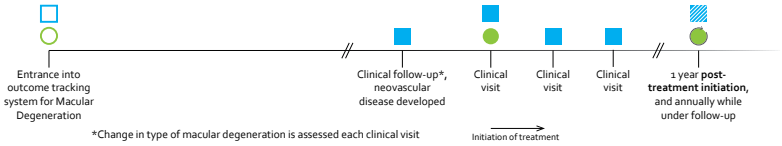
Follow-Up Timeline and Sample Questionnaires

The following timeline illustrates when Standard Set variables should be collected from patients, clinicians, and administrative sources.

Example 1: Patient with neovascular disease, receives treatment post diagnosis



Example 2: Patient with dry AMD, does not receive treatment and develops neovascular disease after certain period of time



*Change in type of macular degeneration is assessed each clinical visit

The following questionnaires should be administered at the indicated time points

- Baseline Patient-Reported Form (link)
- Baseline Clinical Form (link)
- Each Clinical Visit Clinical Form (link)
- 1 Year Post Initiation of Treatment Patient-Reported Form (link)
- Annual (While Under Follow-Up) Patient-Reported Form (link)
- Annual (From Baseline) Clinical Form (link)

1

Collecting Patient-Reported Outcome Measures

For reference, below is the list of validated surveys used in ICHOM's Macular Degeneration patient questionnaires along with information about them. To facilitate your process of collecting these suggested items, ICHOM has compiled each of these surveys along with additional questions into comprehensive sample questionnaires. The recommended reporting for visual acuity is in LogMAR. To facilitate conversion from Snellen into LogMAR acuity scores, a conversion table is available as a part of this Reference Guide

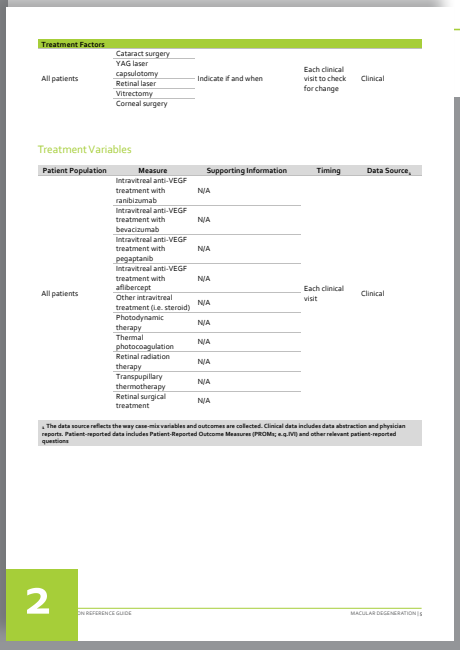
Macular Degeneration Survey Used	Licensing Information
Impact of Vision Impairment Questionnaire (IVI)	The IVI includes costs for commercial use, and requires an agreement license. Contact Prof. Ecosse Lamoureux at ecosse@unimelb.edu.au for more information.

1 With each Standard Set, we have now developed electronic sample questionnaires to give users a natural feel for the Standard Set in practice.

2 We also now include lists of condition-specific, main intervention types to segment patients for analysis.

3 Where available and approved by license, we have included scoring guides to assist interpretations of patient-reported outcomes (PROMs).

4 We have developed comprehensive data dictionaries for each condition to ensure consistency in measurement and to pave the way for benchmarking in the future.



Treatment Factors

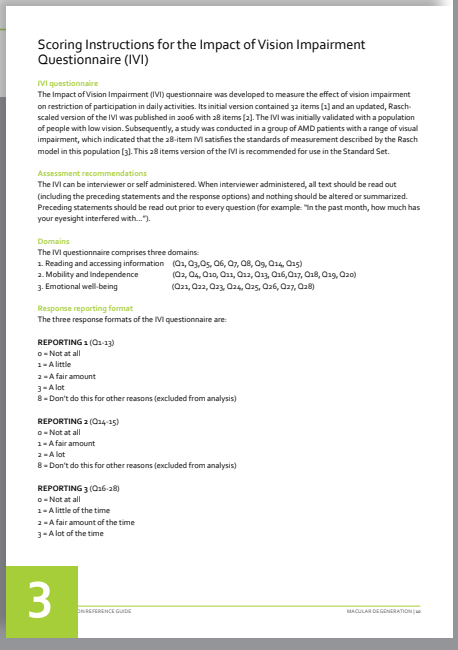
All patients	Cataract surgery YAG laser capsulotomy Retinal laser Vitrectomy Corneal surgery	Indicate if and when	Each clinical visit to check for change	Clinical

Treatment Variables

Patient Population	Measure	Supporting Information	Timing	Data Source[1]
All patients	Intravitreal anti-VEGF treatment with ranibizumab	N/A	Each clinical visit	Clinical
	Intravitreal anti-VEGF treatment with bevacizumab	N/A		
	Intravitreal anti-VEGF treatment with pegaptanib	N/A		
	Intravitreal anti-VEGF treatment with aflibercept	N/A		
	Other intravitreal treatment (i.e. steroid)	N/A		
	Photodynamic therapy	N/A		
	Thermal photocoagulation	N/A		
	Retinal radiation therapy	N/A		
	Transpupillary thermotherapy	N/A		
	Retinal surgical treatment	N/A		

[1] The data source reflects the way case-mix variables and outcomes are collected. Clinical data includes data abstraction and physician reports. Patient-reported data includes Patient-Reported Outcome Measures (PROMs; e.g./VI) and other relevant patient-reported questions

2



Scoring Instructions for the Impact of Vision Impairment Questionnaire (IVI)

IVI questionnaire

The Impact of Vision Impairment (IVI) questionnaire was developed to measure the effect of vision impairment on restriction of participation in daily activities. Its initial version contained 32 items [1] and an updated, Rasch-scaled version of the IVI was published in 2006 with 28 items [2]. The IVI was initially validated with a population of people with low vision. Subsequently, a study was conducted in a group of AMD patients with a range of visual impairment, which indicated that the 28-item IVI satisfies the standards of measurement described by the Rasch model in this population [3]. This 28 items version of the IVI is recommended for use in the Standard Set.

Assessment recommendations

The IVI can be interviewer or self administered. When interviewer administered, all text should be read out (including the preceding statements and the response options) and nothing should be altered or summarized. Preceding statements should be read out prior to every question (for example: "In the past month, how much has your eyesight interfered with…").

Domains

The IVI questionnaire comprises three domains:

1. Reading and accessing information	(Q1, Q3,Q5, Q6, Q7, Q8, Q9, Q14, Q15)
2. Mobility and Independence	(Q2, Q4, Q10, Q11, Q12, Q13, Q16,Q17, Q18, Q19, Q20)
3. Emotional well-being	(Q21, Q22, Q23, Q24, Q25, Q26, Q27, Q28)

Response reporting format

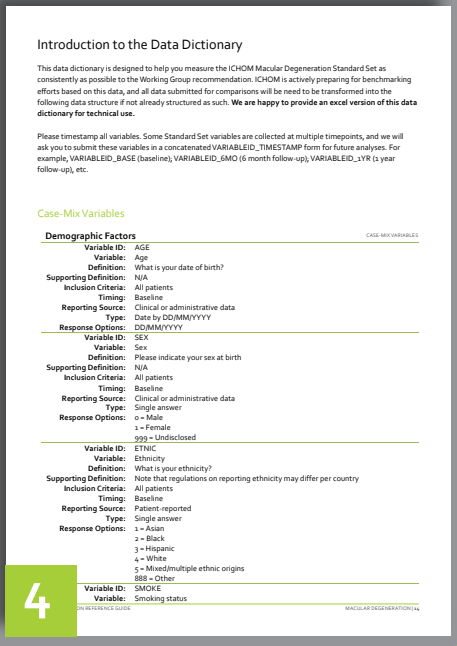
The three response formats of the IVI questionnaire are:

REPORTING 1 (Q1-13)
0 = Not at all
1 = A little
2 = A fair amount
3 = A lot
8 = Don't do this for other reasons (excluded from analysis)

REPORTING 2 (Q14-15)
0 = Not at all
1 = A fair amount
2 = A lot
8 = Don't do this for other reasons (excluded from analysis)

REPORTING 3 (Q16-28)
0 = Not at all
1 = A little of the time
2 = A fair amount of the time
3 = A lot of the time

3



Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Macular Degeneration Standard Set as consistently as possible to the Working Group recommendation. ICHOM is actively preparing for benchmarking efforts based on this data, and all data submitted for comparisons will be need to be transformed into the following data structure if not already structured as such. **We are happy to provide an excel version of this data dictionary for technical use.**

Please timestamp all variables. Some Standard Set variables are collected at multiple timepoints, and we will ask you to submit these variables in a concatenated VARIABLEID_TIMESTAMP form for future analyses. For example, VARIABLEID_BASE (baseline); VARIABLEID_6MO (6 month follow-up); VARIABLEID_1YR (1 year follow-up), etc.

Case-Mix Variables

Demographic Factors CASE-MIX VARIABLES

Variable ID:	AGE
Variable:	Age
Definition:	What is your date of birth?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Clinical or administrative data
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY
Variable ID:	SEX
Variable:	Sex
Definition:	Please indicate your sex at birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Clinical or administrative data
Type:	Single answer
Response Options:	0 = Male 1 = Female 999 = Undisclosed
Variable ID:	ETNIC
Variable:	Ethnicity
Definition:	What is your ethnicity?
Supporting Definition:	Note that regulations on reporting ethnicity may differ per country
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Asian 2 = Black 3 = Hispanic 4 = White 5 = Mixed/multiple ethnic origins 888 = Other
Variable ID:	SMOKE
Variable:	Smoking status

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IMPLEMENTATION UPDATE

ICHOM welcomes new Vice President, expands offerings

At the end of last year, we were thrilled to welcome Jess Aisenbrey as our new Vice President of Implementation. Before earning an MBA from Wharton and an MPA from Harvard Kennedy School of Government, Jess discovered her passion for improving health care while working for a community health provider in New York City. "I'm excited about outcomes measurement because it is truly the key that will unlock the power of value-based health care," Jess says. "Measuring patient outcomes in a standardized way will enable hospitals and health care systems to curb inefficiencies and – most importantly – to improve the results that patients care about most."

Jess' key role at ICHOM is to support providers around the world as they navigate the journey toward outcomes measurement. Recognizing the wide range of goals among these organizations, ICHOM offers **three levels of implementation support**, each designed to promote the integration of one or more of the Standard Sets into routine care processes. For more information on these offerings, we encourage you to review the details below and to reach out to us at implement@ichom.org.

1. Reference Guides

- Detailed, comprehensive Reference Guides for every Standard Set are freely available. Click here to learn more.

Free download

2. Implementation Network

- Online library of knowledge and tools
- International virtual community
- Essential information about outcomes measurement and how to implement

3. Tailored Support

- Customized support options are available from ICHOM and its partners to address specific challenges, accelerate implementation, and ensure success.

For details, please contact us at implement@ichom.org.

BECOME A SPONSORING PARTNER

Benefits of partnering with ICHOM

To help advance our relationships with our current Sponsoring Partners – and to gain new ones – we have developed the following membership model.

ICHOM Sponsoring Partners enjoy several benefits

- Members of your team will have access to seats at the ICHOM conference
- Your organization's logo will be showcased on our website and in key communications
- You will have the opportunity to highlight your commitment to outcomes measurement and value-based health care by placing the "ICHOM Sponsoring Partner" logo on your organization's website and other materials.
- Access to the ICHOM Implementation Network

Gold and Platinum Sponsoring Partners also enjoy engagement with ICHOM regarding the journey toward value-based health care. Engagement may include on-site workshops, lectures, or implementation kickoff meetings.

Levels of Sponsorship

PLATINUM	GOLD	SILVER	BRONZE
$100,000 +	$50,000 - $99,999	$25,000 - $49,999	$10,000 - $24,999

To become a Sponsoring Partner, contact us at ichomteam@ichom.org

PLATINUM

GOLD

Carl Bennet AB

SILVER

BRONZE

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