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THE ROAD TO POLICY AND CLINICAL INTEGRATION
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PN40 - Evaluating new genetic and genomic tests in Health Technology Assessment: How to define and measure value?

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Wednesday, June 28 | 9:10 – 10:25AM

Dr Simon Fifer
Director of Research & Innovation, CaPPRe

Dr Jack Nunn
Director & Founder, Science For All; La Trobe University; MSAC member

A/Prof Sarah Norris
Associate Professor, University of Sydney; MSAC member

Nicole Millis
CEO, Rare Voices Australia; Consumer Nominee, Life Saving Drugs Program Expert Panel

Gillian Mason
Hunter Medical Research Institute; MSAC consumer member

Prof Deborah Marshall
Professor, University of Calgary

Panel flow - How to define and measure value?

Jack: Setting the scene – defining value

Sarah: Issues from a policy perspective

Nicole: Why is this important – patient perspective

Gillian: Personal perspective – evidence gaps

Deborah: How to measure value?

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Health Technology Assessment: Who is involving who?

Dr Jack Nunn
Director & Founder, Science For All; La Trobe University;
Member, Medical Services Advisory Committee (MSAC)

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An expert is in the eye of the beholder

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I speak from personal and professional experience

Today I am not speaking on behalf of any organisations and represent myself

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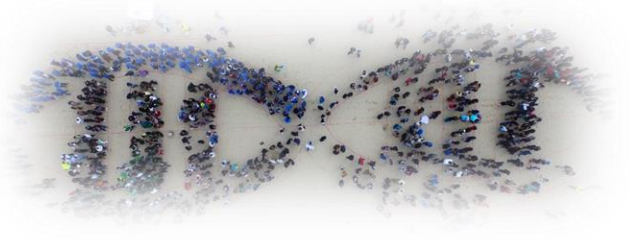
What do we mean 'involving' people?

‘an approach to health technology assessment, where technologies are assessed “with” people rather than “for” them’



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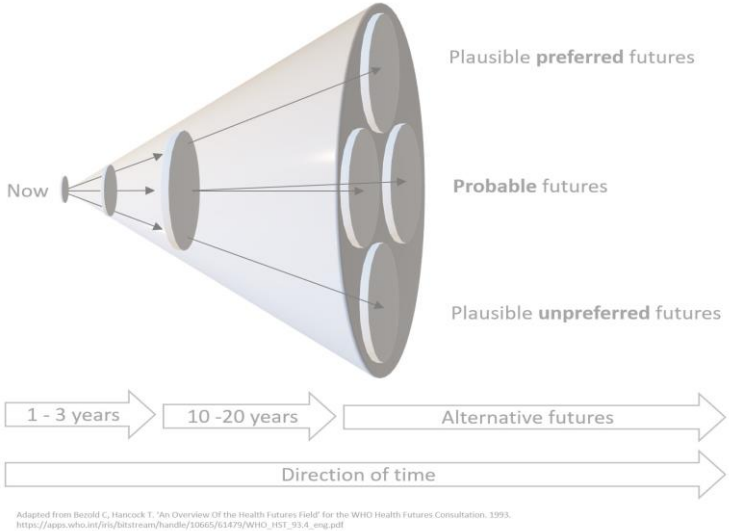
Why involve people?



Adapted from Bezold C, Hancock T. "An Overview Of the Health Futures Field" for the WHO Health Futures Consultation. 1993. https://apps.who.int/iris/bitstream/handle/10665/61479/WHO_HST_93.4_eng.pdf

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Who is involving who?

Who shouldn't be involved in health technology assessment?

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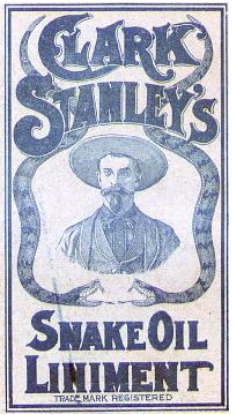

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What are the different stakeholder groupings?

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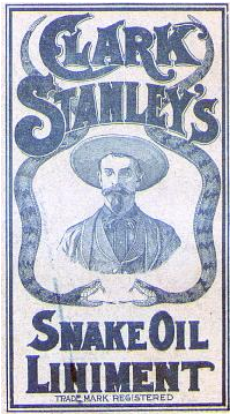

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What are the different stakeholder groupings?
Public? Healthcare professionals? Policy makers? Industry?

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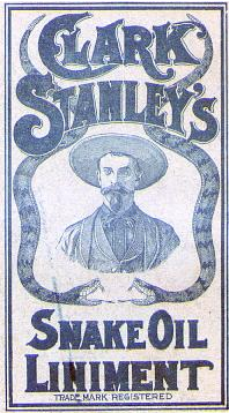

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Who defines value(s), who measures them?

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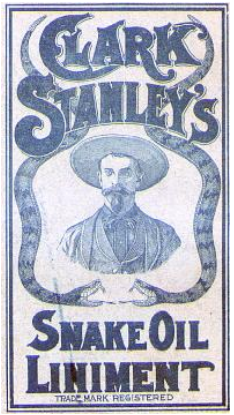

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We need evidence informed HTA processes

- **We need standardised reporting of HTA**

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We need evidence informed HTA processes

- **We need standardised reporting of HTA**
- **We need to report how people with lived experiences have been involved**
  - (annotating phenotype data, contributing to quality of life data)

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We need evidence informed HTA processes

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- **We need standardised reporting of HTA**
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Standardised Data on Initiatives

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We need to provide resources for inclusive and accessible involvement

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The difference between value and 'values'?

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The difference between value and 'values'?

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The difference between value and 'values'?

"the unique ethical issues with genetic testing for hearing loss"

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The difference between value and 'values'?

Who decides who decides what is 'ethical'?

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Summary

- We should **report health technology assessment processes around the world in a standard way**, including evidence assessment processes and **how different stakeholders have been involved.**

- This will allow **evidence informed ways of conducting HTA in more equitable, transparent and effective ways.**

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Disclosures

- Travel and accommodation funded Australian Federal Department of Health
- Time at the conference is given pro bono by Science for All
- I have never been employed by a for-profit company
- Science for All has never been funded or received payment or in-kind support from any for-profit company (including pharmaceutical companies)

Authorship, acknowledgments and involvement

- This presentation was written by Jack Nunn
- Input was invited from other panel members and integrated into this presentation

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The policy perspective

Sarah Norris
Associate Professor of Practice in HTA, University of Sydney
Member, Medical Services Advisory Committee (MSAC)

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All information presented is taken from publicly available sources, primarily the MSAC website and MSAC Public Summary Documents http://msac.gov.au/internet/msac/publishing.nsf/Content/Home-1

MSAC's experience evaluating genetic and genomic tests for heritable conditions

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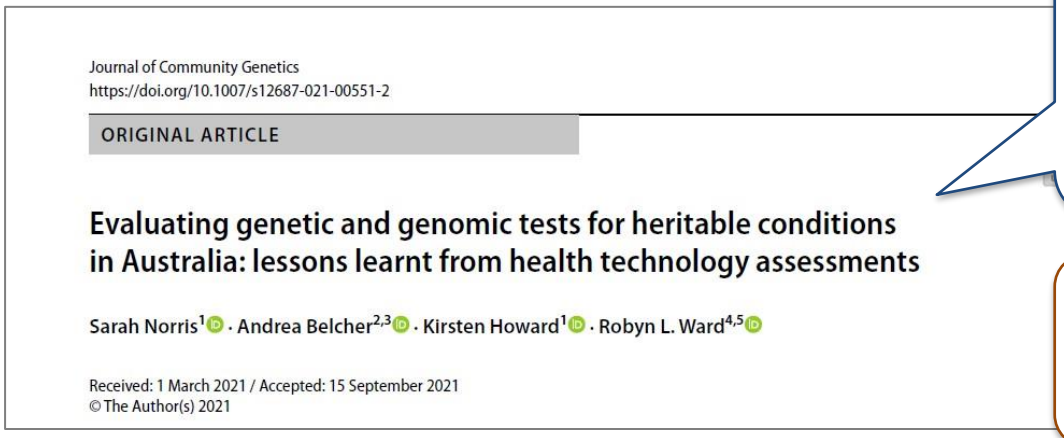

Journal of Community Genetics
https://doi.org/10.1007/s12687-021-00551-2

ORIGINAL ARTICLE

Evaluating genetic and genomic tests for heritable conditions in Australia: lessons learnt from health technology assessments

Sarah Norris[1] · Andrea Belcher[2,3] · Kirsten Howard[1] · Robyn L. Ward[4,5]

Received: 1 March 2021 / Accepted: 15 September 2021

10 published assessments between March 2016 and Nov 2020

+ 3 published assessments since then

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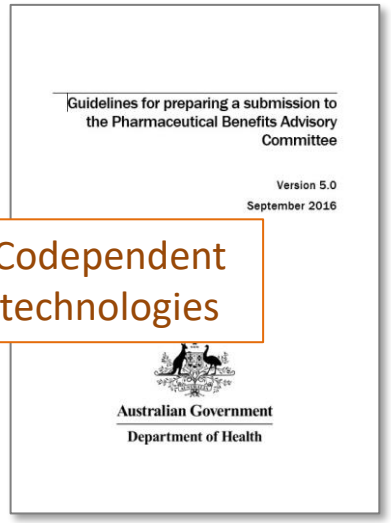
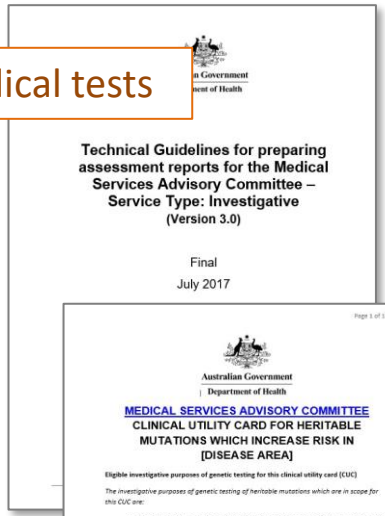
Abbreviated title	Decision
BRCA1/2 for breast and/or ovarian cancer [1411]	Supported
Alport syndrome [1449]	Supported
Childhood syndromes (intellectual disability, global developmental delay) [1476]	Supported
Non-invasive prenatal testing [1492]	Not supported
Increased risk of colorectal or endometrial cancer (Lynch Syndrome, polyposis) [1504]	Supported
Major fetal structural abnormalities [1533]	Supported
Familial hypercholesterolaemia [1534]	Supported
Germline or somatic testing for BRCA1/2 in ovarian cancer for Olaparib [1554]	Supported
Reproductive carrier testing for CF, SMA and FXS [1573]	Supported
Inherited cardiac rhythm disorders [1598]	Supported
Expanded reproductive carrier screening autosomal recessive, X-linked conditions [1637]	Not supported
Targeted carrier screening for Tay-Sachs and related conditions [1671]	Supported
Genetic testing for childhood hearing impairment [1680]	Supported

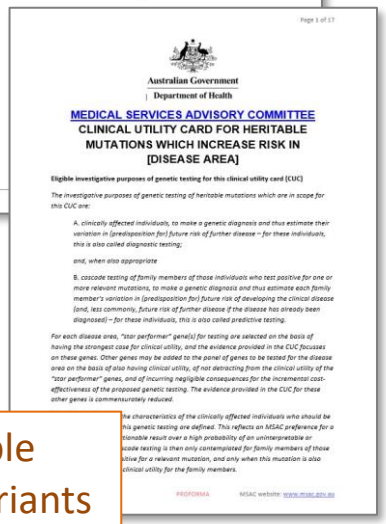
MSAC's approach to these assessments

2016/2017

Medical tests



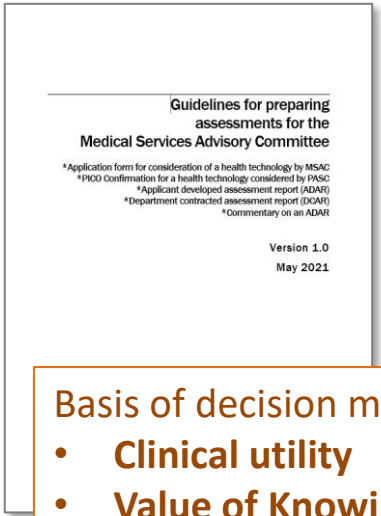




Codependent technologies

Heritable genetic variants

2021



Basis of decision making

- **Clinical utility**
- **Value of Knowing**

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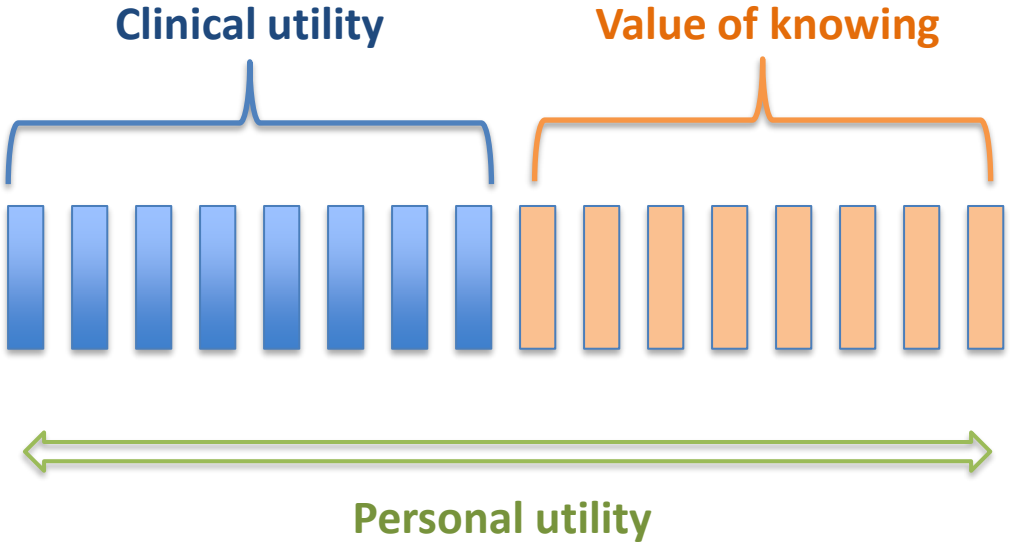
MSAC's framing of Clinical utility, Personal utility and Value of Knowing for medical tests



"This refers to the effects derived from the use of a health technology that may not be characterised by improvements in health, for example, the potential benefits and harms associated with a knowledge of a prognosis or diagnosis"

How MSAC assessments have defined value

For whom	Clinical Utility	Value of knowing
The patient	1. Change in clinical care that improves health outcomes • via treatment or risk reducing strategies 2. Reduced time to diagnosis	4. Access to support services outside the health system facilitated by a molecular diagnosis
The patient's biological relatives	3. Change in clinical care that improves health outcomes • via treatment or risk reducing strategies	5. Information for reproductive planning

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How MSAC assessments have defined value

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Eligibility for a PARP inhibitor for an individual with high-grade ovarian cancer and *BRCA1/2* pathogenic variants

Eligibility for disability support services for a child with intellectual disability or global developmental delay

Early commencement of a PCSK9 inhibitor in an asymptomatic relative at increased risk of familial hypercholesterolaemia

Double mastectomy in an asymptomatic relative with *BRCA1/2* pathogenic variants

Targeted carrier screening for CF, SMA and FXS in individuals and/or their reproductive partner planning a pregnancy

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How the Value of knowing has been defined by MSAC

"Any consequence for the wellbeing of a patient, or their family members or carers, *that does not arise from changes in health outcomes quantified in the clinical utility evidence*. This includes concepts of benefits and harms of knowing, the benefits and harms of naming, and the impact on a patient's or family members'/carers' wellbeing through being able to plan nonhealth resources that come at a cost to the person, and sometimes funders, such as transport, accommodation, education, community care (of self and others, including dependants), equipment, income loss and insurance"

[p18; MSAC Guidelines 2021]

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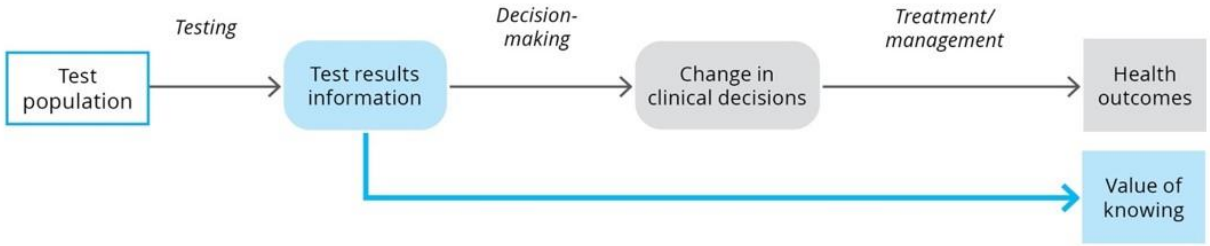
How Value of knowing is being applied

In all circumstances, the clinical claim must relate to health outcomes. An assessment report may state that the clinical claim is accompanied by an *additional* claim for the value of knowing or other relevant considerations.

The PICO to support claims of value of knowing must include outcomes that measure *both* the health-related claim (noninferiority/superiority) and the value of knowing claim



Other examples of the value of knowing

- long-term planning (e.g. education, career, housing, finances)
- increased/decreased sense of control
- psychological (positive or negative) impact on index patient
- stigmatisation or discrimination
- greater understanding of future health care needs
- the ability to connect with others in the same situation

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Implications for policy

✓ Committee has developed **pragmatic ways** to handle limited evidence for rare conditions:

- Exemplar genetic variants
- Exemplar conditions
- Defining analytic validity when multiple molecular methods are used
- Relying on cost-effectiveness ratios based on diagnostic yield when CUA is not reliable

? Faced with **important knowledge gaps** that cannot (and should not) be inferred by the Committee:

- Community views on genomic sequencing
- Ethical aspects, especially in the context of population and prenatal screening
- How to **formally measure** and **incorporate** the **Value of Knowing** in our deliberations

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A rare disease community perspective . . .

Nicole Millis
CEO, Rare Voices Australia
Consumer Nominee, Life Saving Drugs Program Expert Panel

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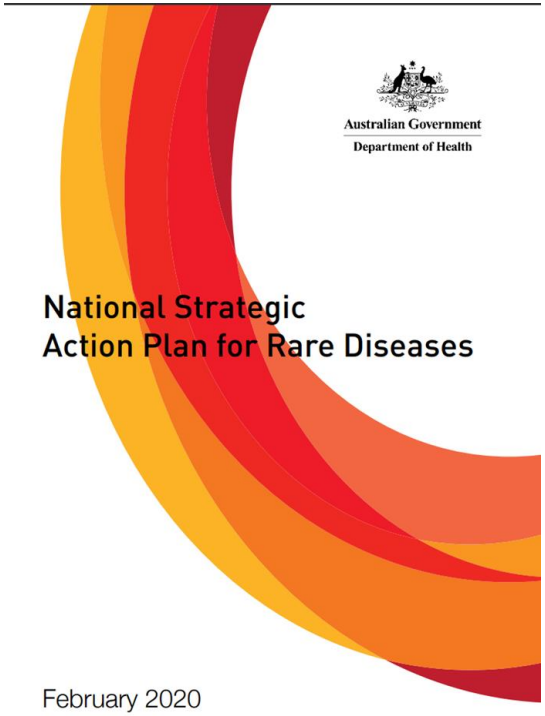
National Strategic Action Plan for Rare Diseases



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*"Reimbursement of health technologies for rare diseases, using models designed for more common diseases, is **challenging**"*

- **smaller patient numbers** impact cost effectiveness
- often **less clinical evidence** available

Australian Government 2020 National Strategic Action Plan for Rare Diseases

Early diagnosis enables

- the best clinical care
- treatment options
- access to services
- peer support
- increased reproductive confidence
- access to participation in clinical trials.

Yet diagnostic delay and misdiagnosis is common.

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Priority 2.2:

Ensure diagnosis of a rare disease is timely and accurate.

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- Action 2.2.1: Ensure all Australians have equitable access to a range of diagnostic tools and tests, providing the best chance of early and accurate diagnosis.

Priority 2.3:

Facilitate increased reproductive confidence.

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Australian Government 2020 National Strategic Action Plan for Rare Diseases

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Priority 2.4:

Enable all Australians to have equitable access to the best available health technology.

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- Action 2.4.1: Develop policy that supports people living with a rare disease to have timely and equitable access to new and emerging health technologies.

- Action 2.4.2: Ensure funding and reimbursement pathways are fit-for-purpose and sustainable for current and new health technologies for rare diseases.

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- Australian Government 2020 National Strategic Action Plan for Rare Diseases

Action 2.1.5:

Embed the voice of people living with a rare disease and their families and carers throughout structures and systems that impact rare diseases.

- Australian Government 2020 National Strategic Action Plan for Rare Diseases

‘Value of Knowing’

Critical for people living with a rare disease because

rare disease = uncertainty

Frequent misdiagnosis/ diagnostic odyssey.

Knowing is often a gateway to care, support, and innovation.

The value of knowing is a principle that should be applied to all HTA policy and methods.

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What else...?

*Value of **reduced burden of treatment**?*

*Value of **innovation**?*

*Value of **time**?*

What else...?

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Patients', and the patience perspective

Gillian Mason

Consumer and Community Involvement Lead, Hunter Medical Research Institute

Consumer Member, MSAC

Disabled, chronically ill human with rare inherited condition

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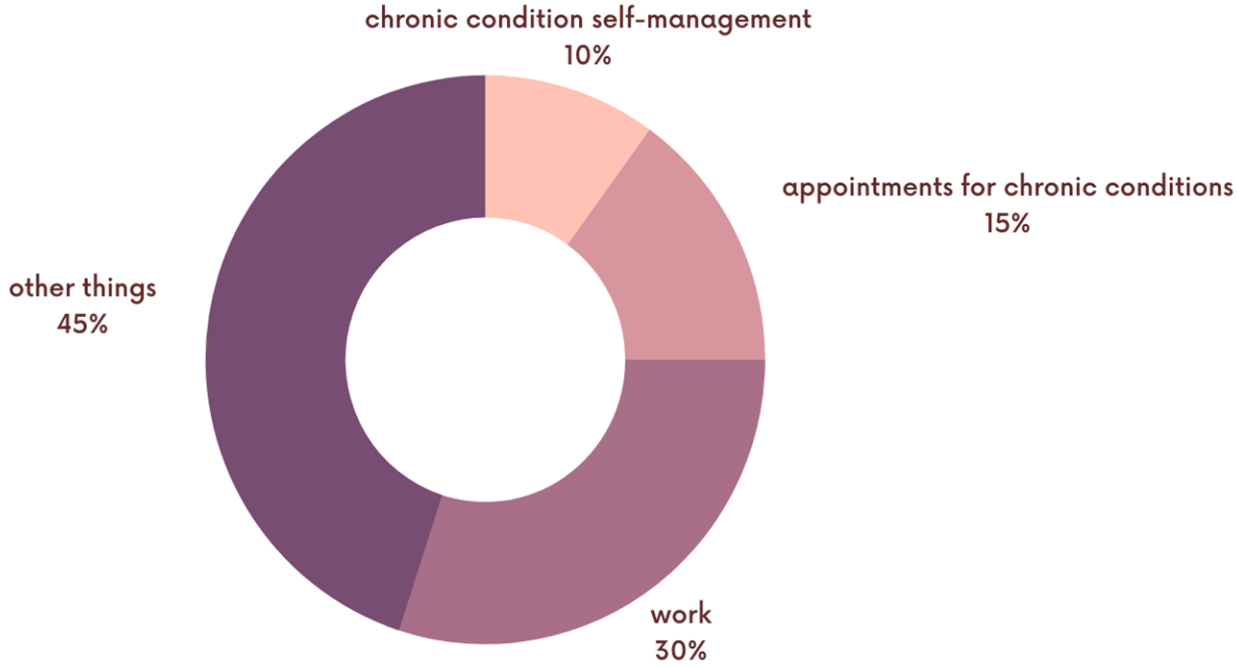
Fully sick

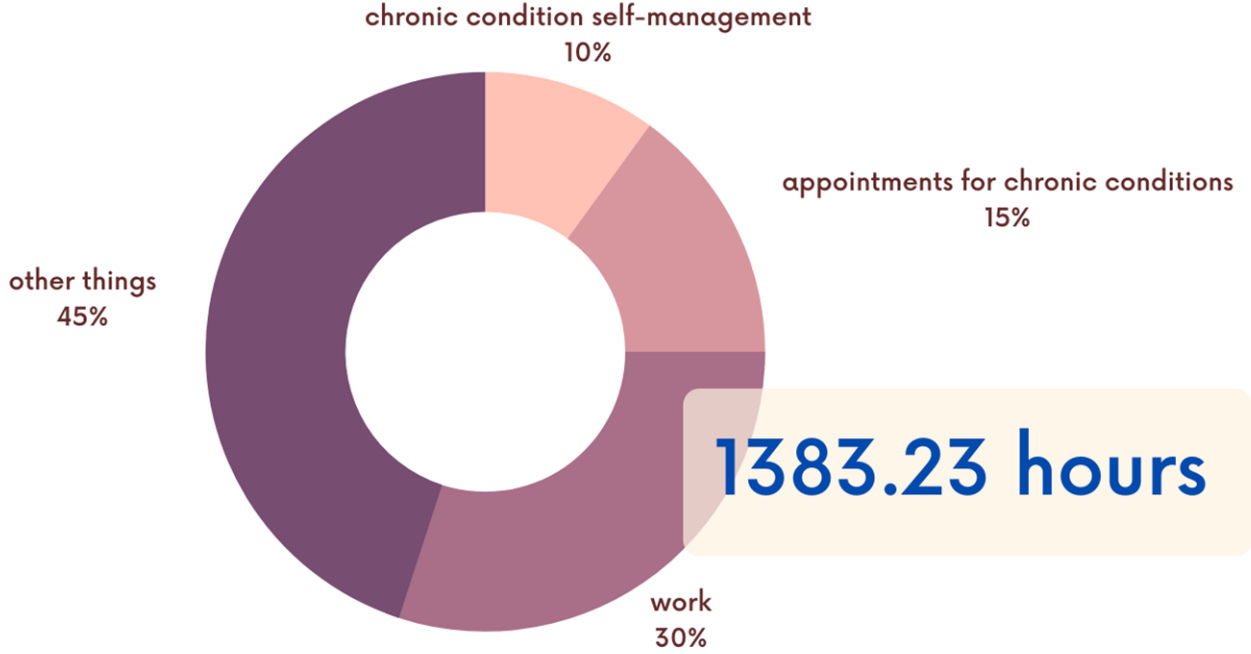
Feb - Nov 2020

8	Hospital admissions
59	Health appointments
31	Telehealth
16	Telephone
13	Videocall

Fully sick – waking hours (year) by activity



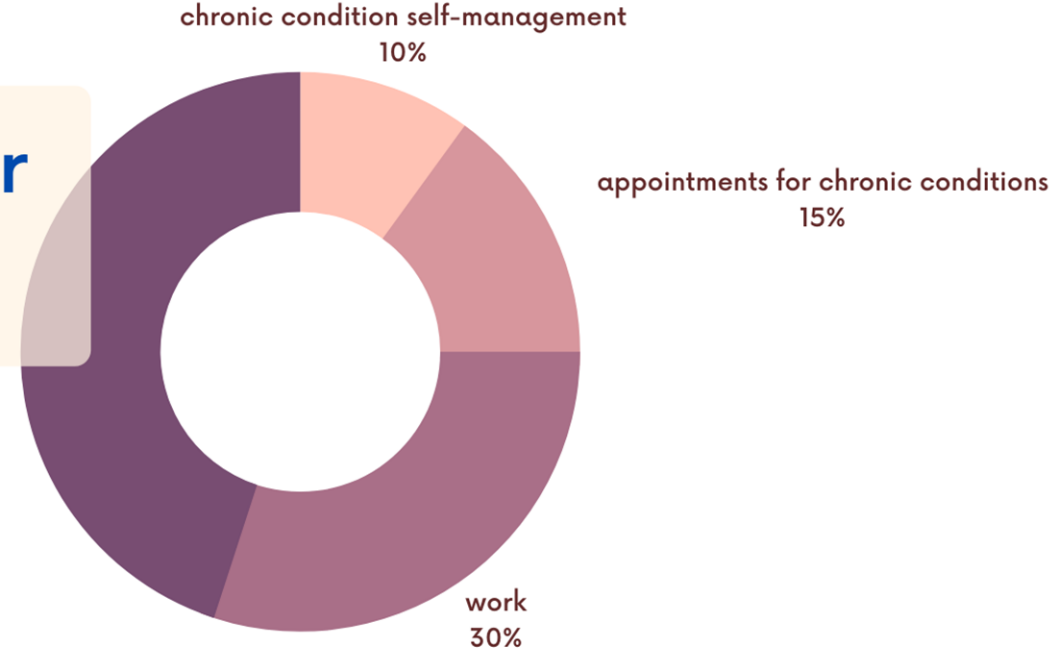
Fully sick – waking hours (year) by activity



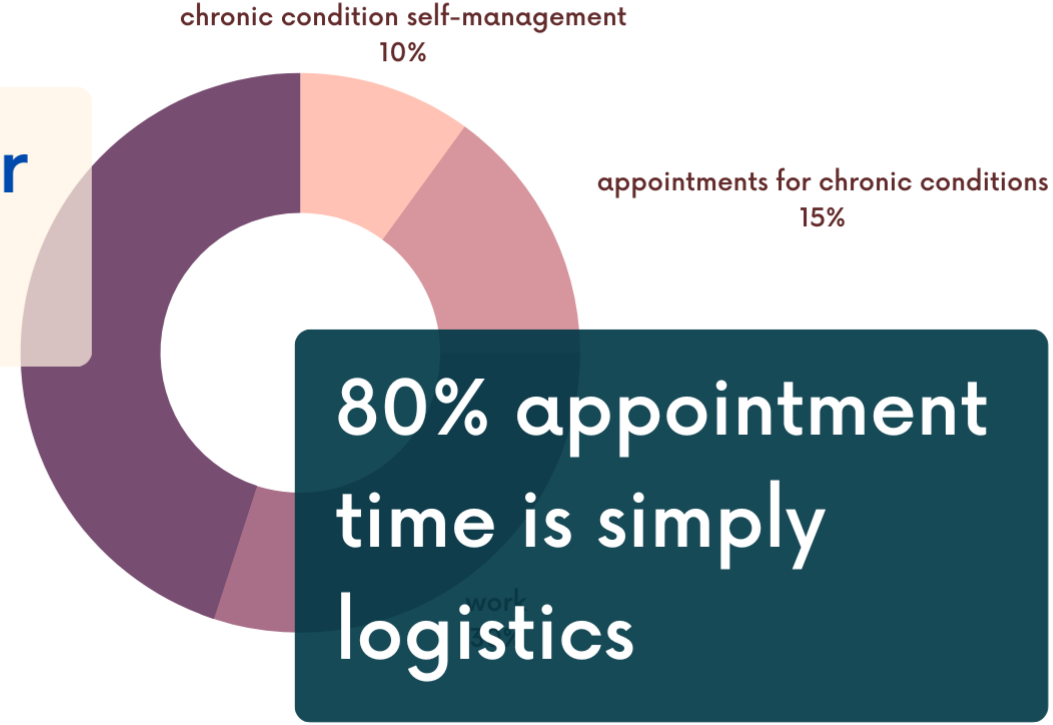
1383.23 hours

Fully sick - waking hours (year) by activity

3.7 hours per day



Fully sick – waking hours (year) by activity



3.7 hours per day

80% appointment time is simply logistics

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Telehealth Savings

saved 46 travel hours in 2020

@gillyminn

Fully sick

01 Chronic illness is **time-consuming** and **unrelenting**

02 **Managed well**, you may be **well-enough** to participate in work, and perhaps even do other things too

03 Participating in the **logistics** of evidence-based chronic condition management **consumes resources**


@gillyminn

What sort of information should I include in my consultation feedback?

The sort of information that might be included in consultation feedback will depend on who is providing the feedback. Organisations representing consumers and carers, or individuals with lived experience of the medical condition(s), technologies and/or services relevant to an application might address:

- How is the medical condition that the proposal applies to currently treated? What are the benefits and/or challenges of existing treatment?
- If the proposed medical technology/service is funded, who should have access to it?
- Do patients already have access to the proposed technology/service? Is access limited due, for example, to geography or out-of-pocket costs? If so, what are the implications of this?
- If you have experience of the proposed technology/service, what benefits did you experience? Were there any negative aspects to the experience?
- If the medical service or technology received public funding, how would this impact consumers and carers?

If you are still unsure about the type of information to include in your consultation feedback, or have queries about other aspects of the MSAC consultation process, support and guidance is available by emailing htaconsumerengagement@health.gov.au.

http://www.msac.gov.au/internet/msac/publishing.nsf/Content/FAQ-01#FAQC1.3

What evidence do we have and what is missing?

- Input from diverse groups that helps us to contextualise evidence
- When 'convenience' and 'access to choices' are *access issues*
- Who has access now to the current accepted practice or comparator?

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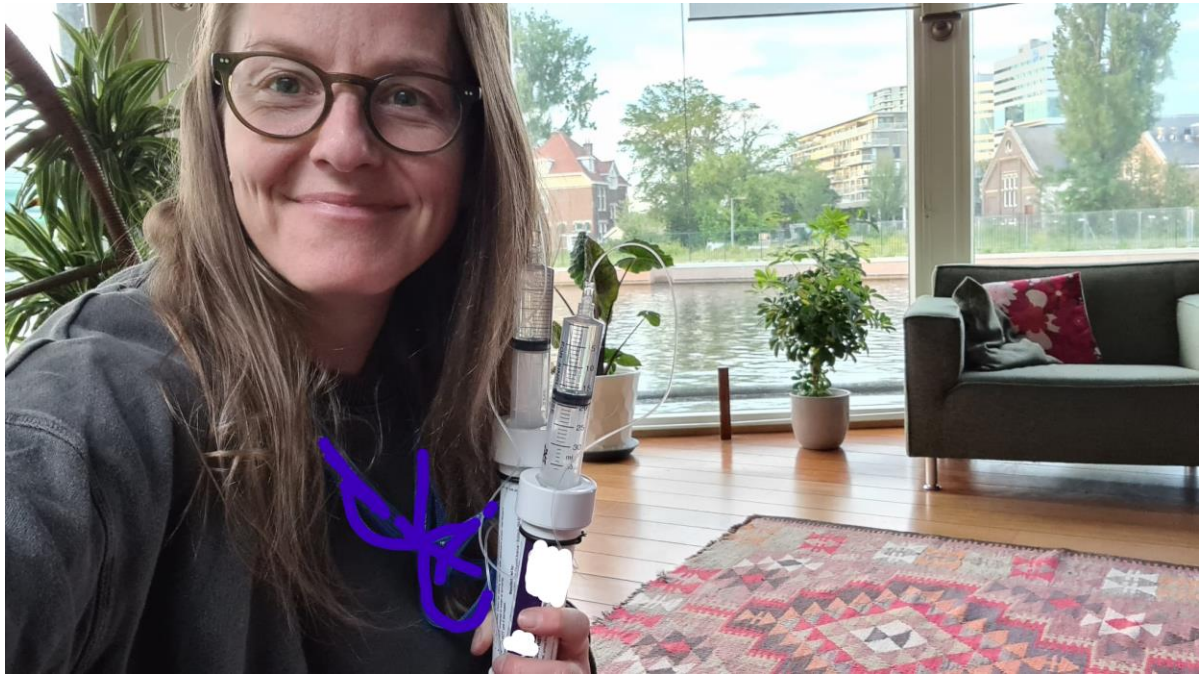

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What evidence do we have and what is missing?

- When patients (and *which* patients) would choose an option that is not in line with the best health outcomes
- Research, including trials and consultation processes that are accessible and feel relevant (personally and to communities)

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value

HMRI

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Preference research methods to measure the value of genomic tests and testing

Deborah A Marshall, PhD

Professor, Cumming School of Medicine, University of Calgary
Scientific Director, Alberta Children's Hospital Research Institute

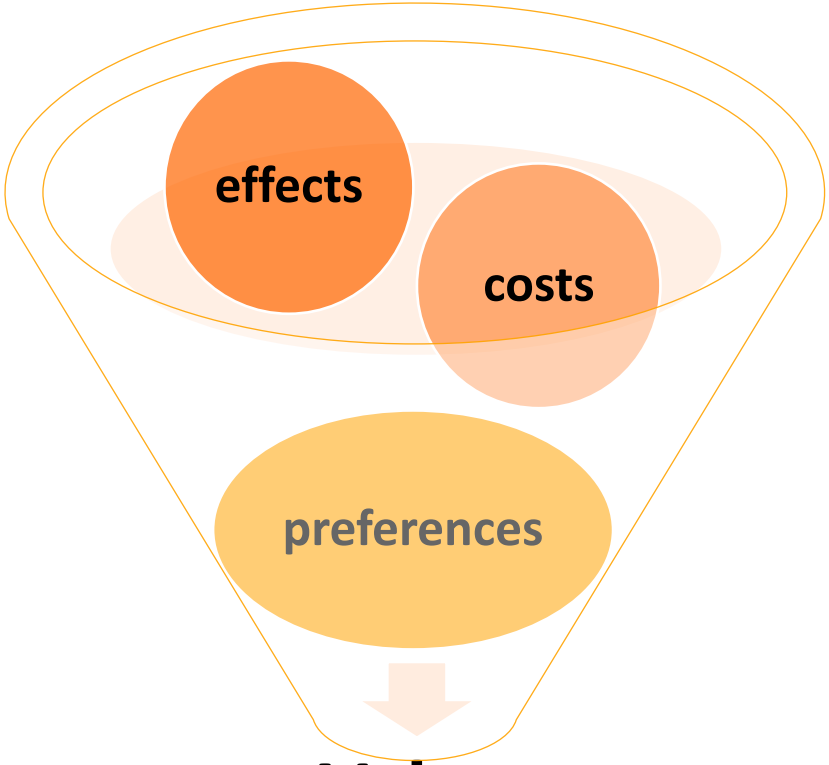
Twitter: @Marshall_HEcon

PN40 Evaluating new genetic and genomic tests in HTA: How to define and measure value?
Wed June 28 @ 9:10-10:25 am

Foundational Concepts:

What is ‘Value’ in Precision Health?

Opportunity Costs – Trade-Offs



Value

Considering both testing and treatment context

Types of Patient Preference Information (PPI) and What Does it Measure (Benefits, Harms, Risks, Non-Health Outcomes)?

Attributes	Relative Importance	Trade-offs Relative Importance
What matters	Order of what matters	How much it matters
Qualitative methods	Quantitative methods	Quantitative methods designed explicitly to capture trade-offs
Patient Priorities	Patient Priorities	Benefit-Risk Assessment Preference Heterogeneity

http://mdic.org/mdicx/#archive;
Medical Device Innovation Consortium (MDIC). 2015 http://mdic.org/wpcontent/uploads/2015/05/MDIC_PCBR_Framework_Web.pdf

Relevance of Preferences in Decision Making

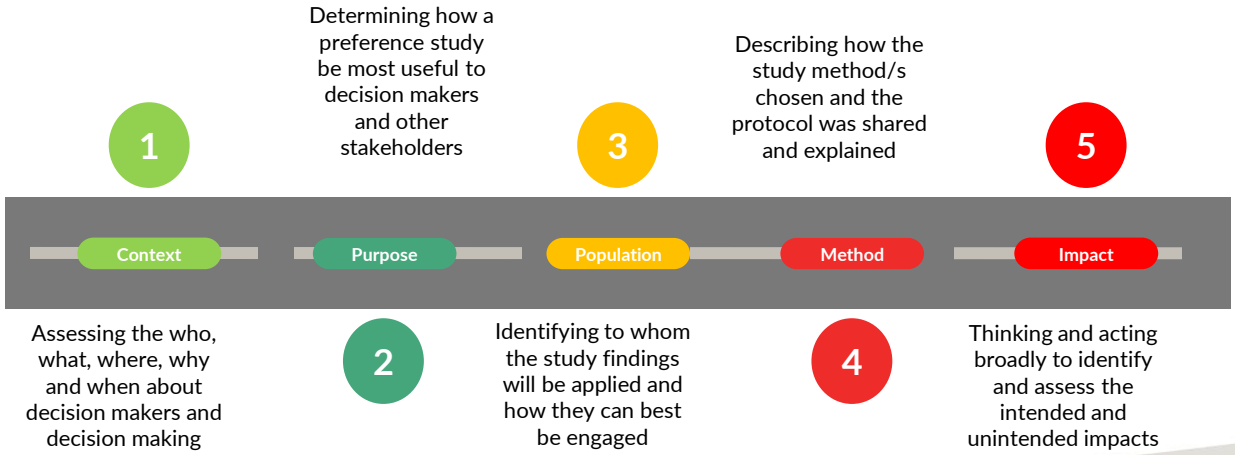
International Expert Task Force

UNIVERSITY OF CALGARY

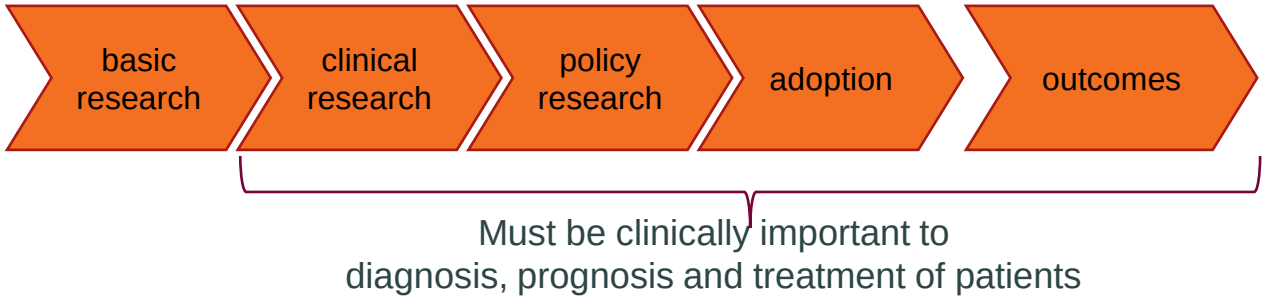
ISPOR Report

A Roadmap for Increasing the Usefulness and Impact of Patient-Preference Studies in Decision Making in Health: A Good Practices Report of an ISPOR Task Force

John F.P. Bridges, PhD, Esther W. de Bekker-Grob, PhD, Brett Hauber, PhD, Sebastian Heidenreich, PhD, Ellen Janssen, PhD, Alice Bast, BA, Janel Hanmer, MD, PhD, Andriy Danyliv, PhD, Eric Low, MSc, Jacoline C. Bouvy, PhD, Deborah A. Marshall, PhD



Challenges to Assessing Value in Genomic Testing



1) What is the value of a diagnosis and time to diagnosis?
2) What is the value (positive and negative) of testing information?
3) Who is affected and who decides what information to share? Beyond testing 'sensitivity' and 'specificity' –downstream consequences of incidental findings?
4) Factors affecting uptake of WGS

- *Phillips KA, Deverka PA, Marshall DA et al. Methodological challenges and solutions for assessing economic value of next generation sequencing tests. Value in Health, 2018; 21(9): 1033-1042; - Husereau D, Marshall DA, Levy AR et al. Health technology assessment and personalized medicine: are economic evaluation guidelines sufficient to support decision making? IJTAHC 2014 30(2): 179-187.*

Value of a Diagnosis and Time to Diagnosis

- Traditional CEAs probably underestimate value of testing
- Diagnostic tests are typically reimbursed based on cost rather than value
- Patients generally prefer to have information than not
  - Even if information cannot direct treatment
  - Patients are willing to pay for diagnostics to obtain health information - 'Value of knowing'; Reassurance that disease is not present; Opportunity to alter behaviour

Example: Review of high quality diagnostic test CEAs reveals deficiencies (n=141):

- **Only 7% considered value or harm of test to patient**
- **Reassurance (n=6)**
- **Worry about false-positives (n=2)**
- **Benefit of reduced uncertainty (n=1)**

- Fang CH, Otero HJ, Greenberg D, Neumann PJ. Cost-Utility Analyses of Diagnostic Laboratory Tests: A Systematic Review. Value in Health 2011;14(8):1010-1018. doi.org/10.1016/j.jval.2011.05.044.; Andrykowski MA, Lightner R, Studts JL, Munn RK. Hereditary cancer risk notification and testing: how interested is the general population? J Clin Oncol. 1997 15(5):2139-48. doi: 10.1200/JCO.1997.15.5.2139; Fryback DG, Thornbury JR. The Efficacy of Diagnostic Imaging. Medical Decision Making. 1991;11(2):88-94. doi:10.1177/0272989X9101100203

Estimating the Value of Whole Exome Sequencing (WES) for Parents of Children with Rare Genetic Diseases: Discrete Choice Experiment

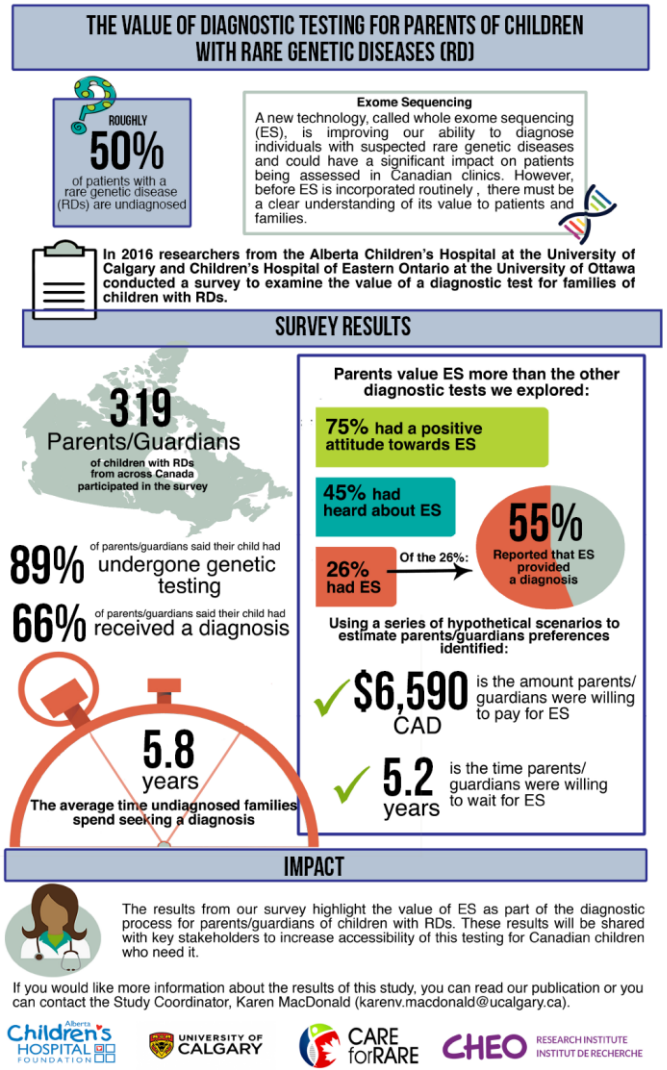
UNIVERSITY OF CALGARY

Suppose you were seeking a diagnosis for your child with a rare genetic disease or suspected genetic condition. Which scenario would you prefer?

	Scenario A	Scenario B	Scenario C
Type of diagnostic test(s) your child would undergo	Series of other tests and procedures	Whole exome sequencing	Operative procedures
Chance of a diagnosis from the test	4 out of 10 	9 out of 10 	6 out of 10 
Negative impact of receiving a diagnosis from the test	Subject to discrimination and/or being labelled by others	Lifestyle restrictions	Receive a poor prognosis
Positive impact of receiving a diagnosis from the test	Changes medical management of the disease	Knowledge about cause, progression and future with disease, and risk to family	Facilitates access to disease-specific services, programming and support groups
Out of pocket cost of diagnostic testing	$10,000	$5,000	$0
Time to obtain an answer (diagnosis or not)	10 years	6 months	3 years
Your choice	○	●	○

What is the Value of a Diagnosis?

- Impact of receiving a diagnosis (increased knowledge and changes in management or access to services was the most valued attribute
- Parents were willing to pay
  - ~US$4,943 for Exome Sequencing and other genetic tests compared with medical and surgical procedures
  - ~US$2,280 for every additional percent increase in the chance of receiving a diagnosis or wait an additional 1.7 years

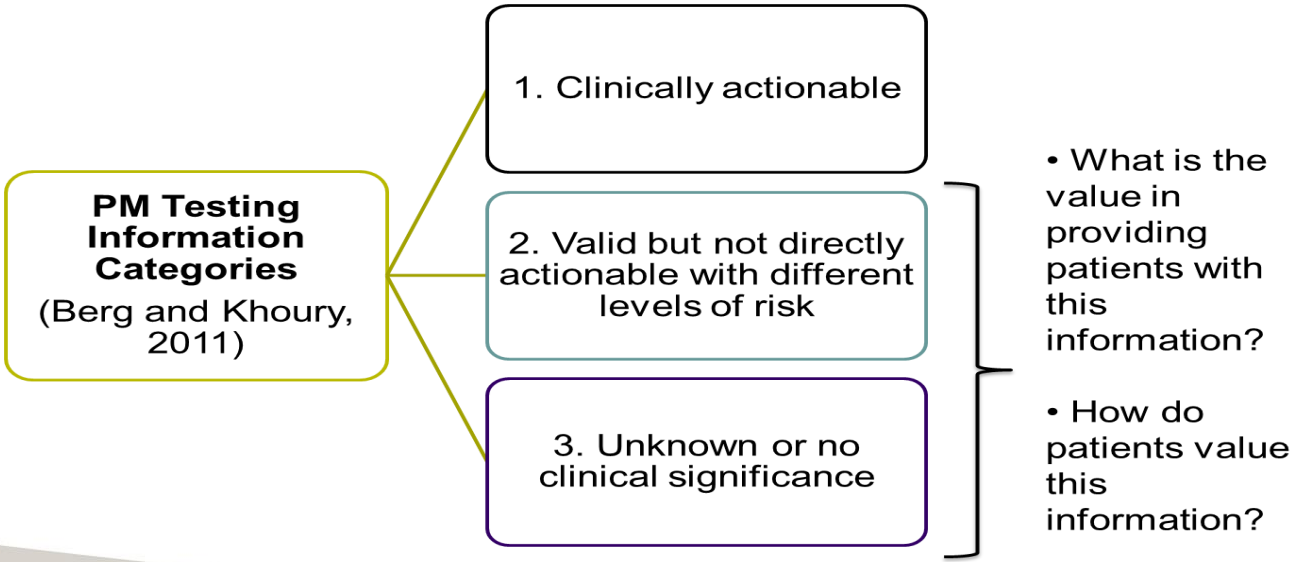


- *Marshall DA, MacDonald KV, Heidenreich S, Hartley T, Bernier FP, Gillespie MK, McInnes B, Innes AM, Armour CM, Boycott KM. The value of diagnostic testing for parents of children with rare genetic diseases. Gen Med 2019 21(11):2662.*

What is the Value of Testing Information?

Value and Preferences for Whole Genome Sequencing (WGS)?

- Joint production - WGS testing reports produce both beneficial and undesirable information
- Incidental information can have negative utility – more information is not always better



- *Berg, Khoury & Evans. Genetics in Medicine, 2011. 13: 499-504.*

Preferences to Value PM Test Information: Whole Genome Sequencing (WGS)

- What is the impact of testing information on family members or society more broadly?
- Exclusion of psychosocial and intergenerational issues from most economic evaluations
- Risk-Benefit Trade-Offs for WGS Reports
  - Who decides what information is reported?
  - What is willingness to pay for actionable and non-actionable information reporting

*Grosse S., Wordsworth S, Payne K. Economic methods for valuing the outcomes of genetic testing: beyond cost-effectiveness analysis. Genet Med 2008;**10**, 648–654 (2008).doi.org/10.1097/GIM.0b013e3181837217*

Who Decides and What are people willing-to-pay for WGS information?

Methods

US nationally representative online survey (n=410 adults)

- Rank preferences for who decides (expert panel, your doctor, you)
- Value of information about variants with varying levels of clinical usefulness using willingness-to-pay contingent valuation questions.

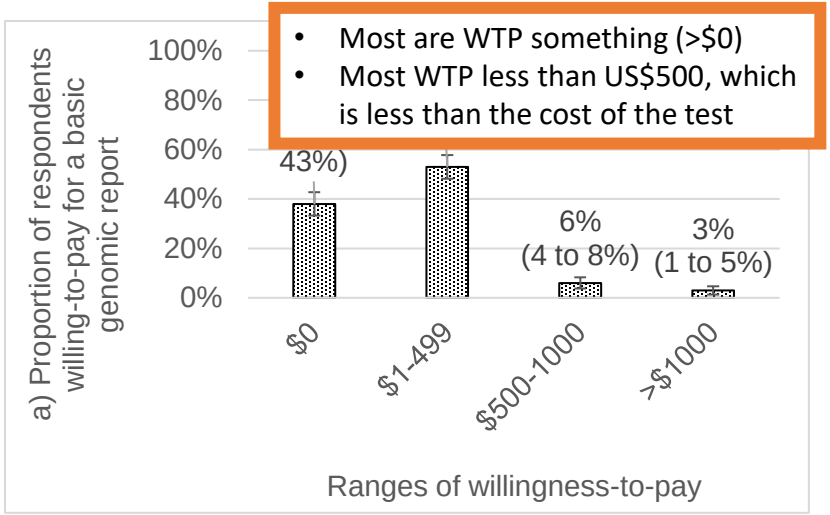
Who Decides?

- 43% (n=170) preferred to decide for themselves about what information is included in the basic genomic report
- 34% (n=140) preferred that their primary-care physicians decided
- 23% (n=93) preferred that a panel of experts interpret the information contained in the basic genomic report.

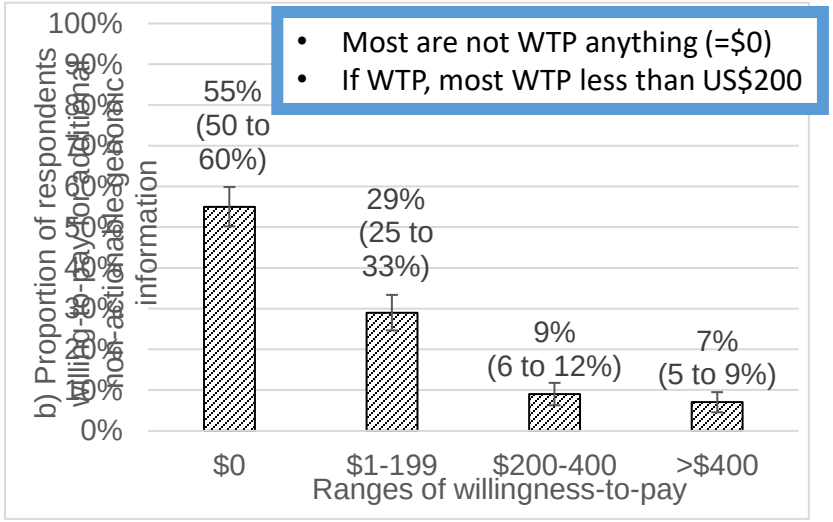
- Marshall DA, Gonzalez JM, MacDonald KV, Johnson FR. Estimating Preferences in the Context of Complex Health Technologies: Lessons Learned and Implications for Personalized Medicine. Value in Health, 2017; 20(1): 32-39.

- Marshall DA, Gonzalez JM, Johnson FR, MacDonald KV, Pugh A, Douglas MP, Phillips KA. Who decides and what are people willing-to-pay for whole genome sequencing information? Genetics in Medicine. 2016; 18(12): 1295-1302. doi:10.1038/gim.2016.61.

Willingness to Pay for Basic WGS Report



Willingness to Pay for Additional (Non-Actionable) Gene Variants



CONCLUSION:

- Despite valuing actionable information more, some respondents perceive genetic information could negatively impact them.
- Heterogeneity in preferences should be considered in the development of WGS policies, particularly in integrating patient preferences with PM and shared decision making.

Factors Affecting Uptake of Genetic Testing for Heritable Conditions in Colorectal Cancer

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Methods: Web-enabled choice-format DCE (n=355 US adults > 50 years)

Conclusions: If false negative test results are unlikely and results are shared with a primary care physician, the majority would have genetic testing.

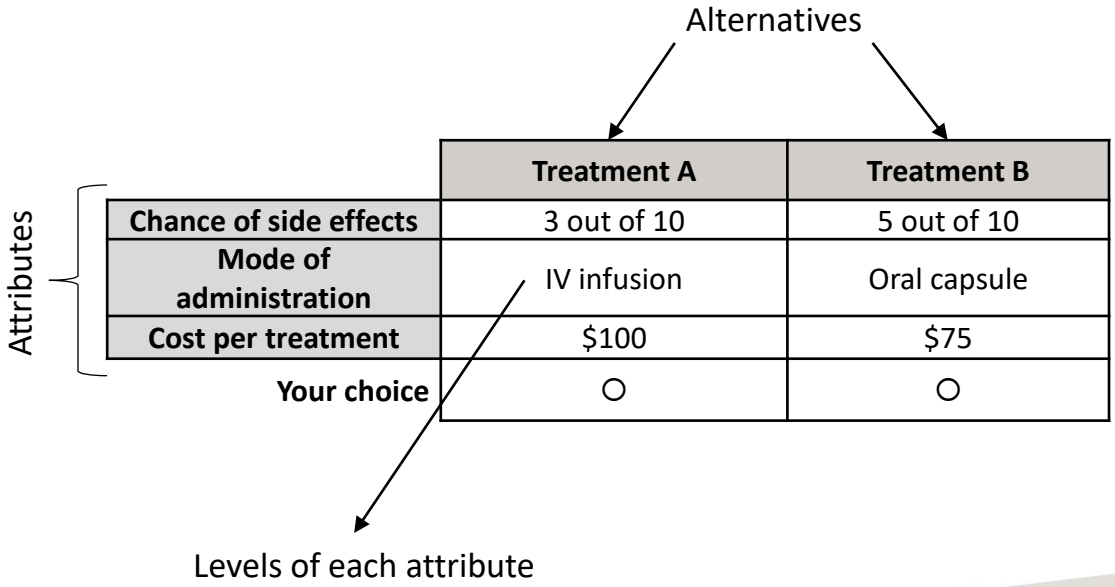
Characteristic	Best Scenario	Worst Scenario
Risk of False negative Test	No false negatives	20% false negatives
Privacy Who sees test results?	Primary Care physician	Disclosed to insurance company
% Who Would Have Genetic Testing to reduce the risk of dying of CRC	97% (95-99%)	41% (25-57%)

-Knight SJ, Mohamed AF, Marshall DA, Ladabaum U, Phillips KA, Walsh JME. Value of genetic testing for hereditary colorectal cancer in a probability-based US online sample. Medical Decision Making 2015;35(6):734-744

Discrete Choice Experiment (DCE) Example

- Respondents choose between alternatives (i.e., treatments) in a series of questions called ‘choice tasks’
- Each alternative is different and includes features (‘attributes’) of the decision (i.e., treatment side effects, dosing, chance of success)
- Responses reveal the weight respondents attach to attributes of the treatment/intervention

Suppose you were considering treatment for metastatic colorectal cancer. Which of the treatment options below would you choose if these were your only options?



	Treatment A	Treatment B
Chance of side effects	3 out of 10	5 out of 10
Mode of administration	IV infusion	Oral capsule
Cost per treatment	$100	$75
Your choice	○	○

Health Economics Value Framework

Framework defined potential for return on investment across four major areas

- **Diagnostic benefit**: The identification of pathogenic or likely pathogenic variants in known disease genes
- **Clinical benefit**: Changes in the medical or surgical management of patients as a result of the diagnosis being made
- **Clinical trial benefit**: Changes related to the improvement of clinical trial operations
- **Personal benefit**: The presence of non-clinical outcomes that are important from a personal point of view to patients.

- Belsey J, Chaihorsky L, Chediak L, Currie GR, Goranitis I, Marshall DA. Global Data Access for Solving Rare Disease: A Health Economics Value Framework. World Economic Forum, February, 2020. (http://www3.weforum.org/docs/WEF_Global_Data_Access_for_Solving_Rare_Disease_Report_2020.pdf)

Example of co-designed genomics preference study

The members of this panel are currently collaborating on the design of a **DCE-based preference study** to help inform future HTA assessments related to genomic testing

- **Research question**: how do people impacted by rare genetic conditions value genomic testing? What is the relative value of health and non-health outcomes of tests?
- **Study population**
    - Patients - people living with rare genetic conditions
    - Carers of patients (e.g. spouse, parent)
- **Recruitment plan:** recruitment led by Rare Voices Australia (RVA) and their research partners who represent different rare disease communities across Australia

Example of co-designed genomics preference study: draft attributes for DCE

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DCE 1

- Chance of diagnostic benefits
- Chance of treatment benefits
- Chance of personal benefits
- Links to future research
- Cost

DCE 2

- Whether secondary findings are shared with you
- Who decides what secondary findings are shared with you
- Who else findings are shared with
- Who stores your data
- Where the data is stored
- Cost

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In addition to the DCE, the survey will also include demographic questions to capture priority populations as identified in the National Strategic Action Plan for Rare Diseases: (e.g. Indigenous, rural/regional, CALD, low SES)

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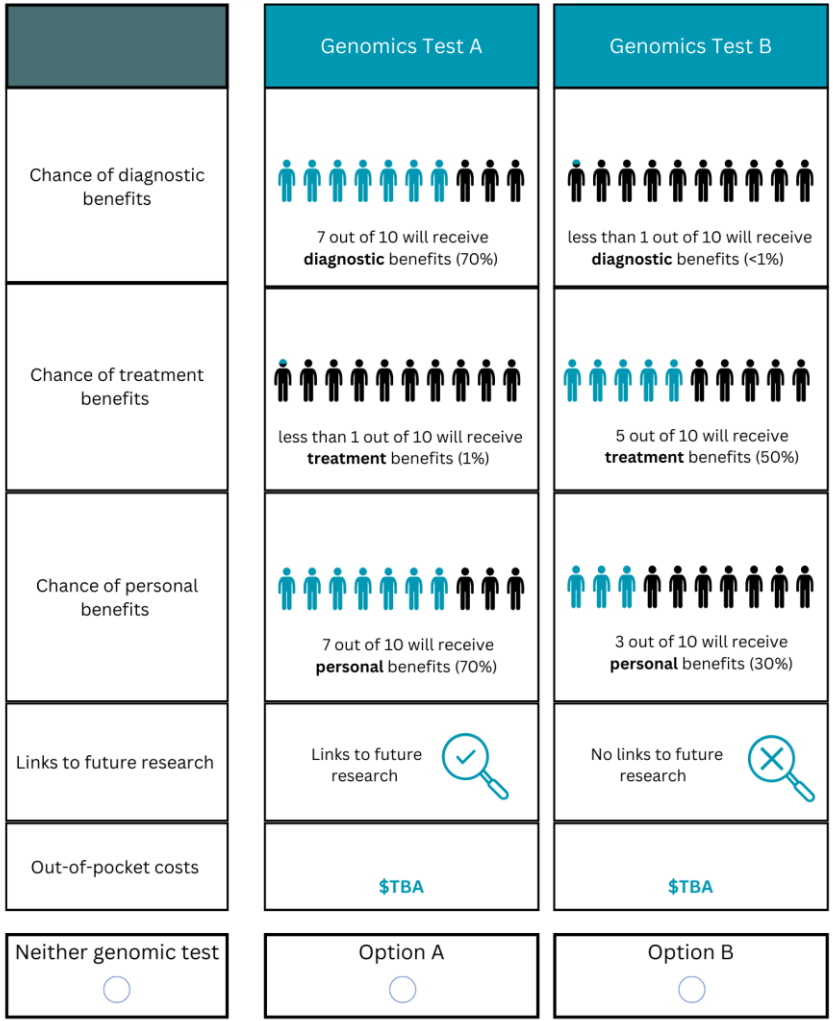
Example of co-designed genomics preference study: example of DCE 1



Example of co-designed genomics preference study: example of DCE 2

	Genomics Test A	Genomics Test B
Secondary findings shared with you?	Yes — Your doctor decides what is shared with you	Yes — You decide what is shared with you
Findings shared with others?	No — No requirement - The decision is up to you	Yes — Requirement for data to be shared with researchers
Who stores your data?	Private organisation	Government organisation
Where is the data stored?	Overseas	In Australia
Out-of-pocket costs	$TBA	$TBA
	Neither genomic test ◯	Option A ◯	Option B ◯

Thank you!

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Prof Deborah Marshall
damarsha@ucalgary.ca

Attribute name	Description
Chance of diagnostic benefits	The chance of doctors identifying the specific gene(s) related to your disease, including providing a more accurate diagnosis and information about the cause of the disease
Chance of treatment benefits	The chance of improving health outcomes by being able to choose a more targeted treatment or disease management pathway
Chance of personal benefits	Non-medical outcomes that may be important from a personal point of view, such as those relating to the inherent value of information, increasing personal knowledge, and being able to make plans for one's family and the future
Links to future research	Whether the test results can be used to advance researchers' understanding of the disease and contribute to clinical trials, which could help you/the person you care for, and others, in the future.
Out-of-pocket cost	The amount you would have to pay 'out of pocket' for this test (the amount not covered by Medicare or your insurer, if you have one)