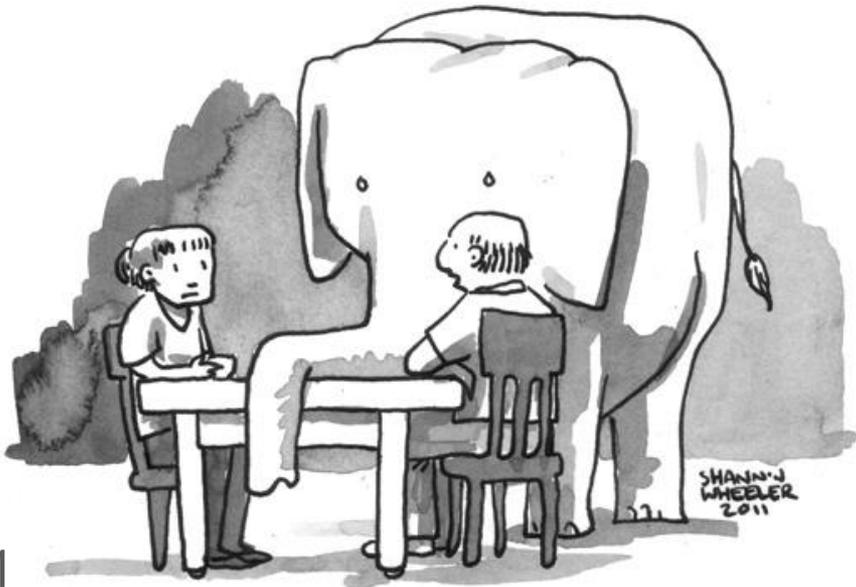


An Elephant in the Room: Advance Care Planning in Dementia

Dr Oleg Kiriaev

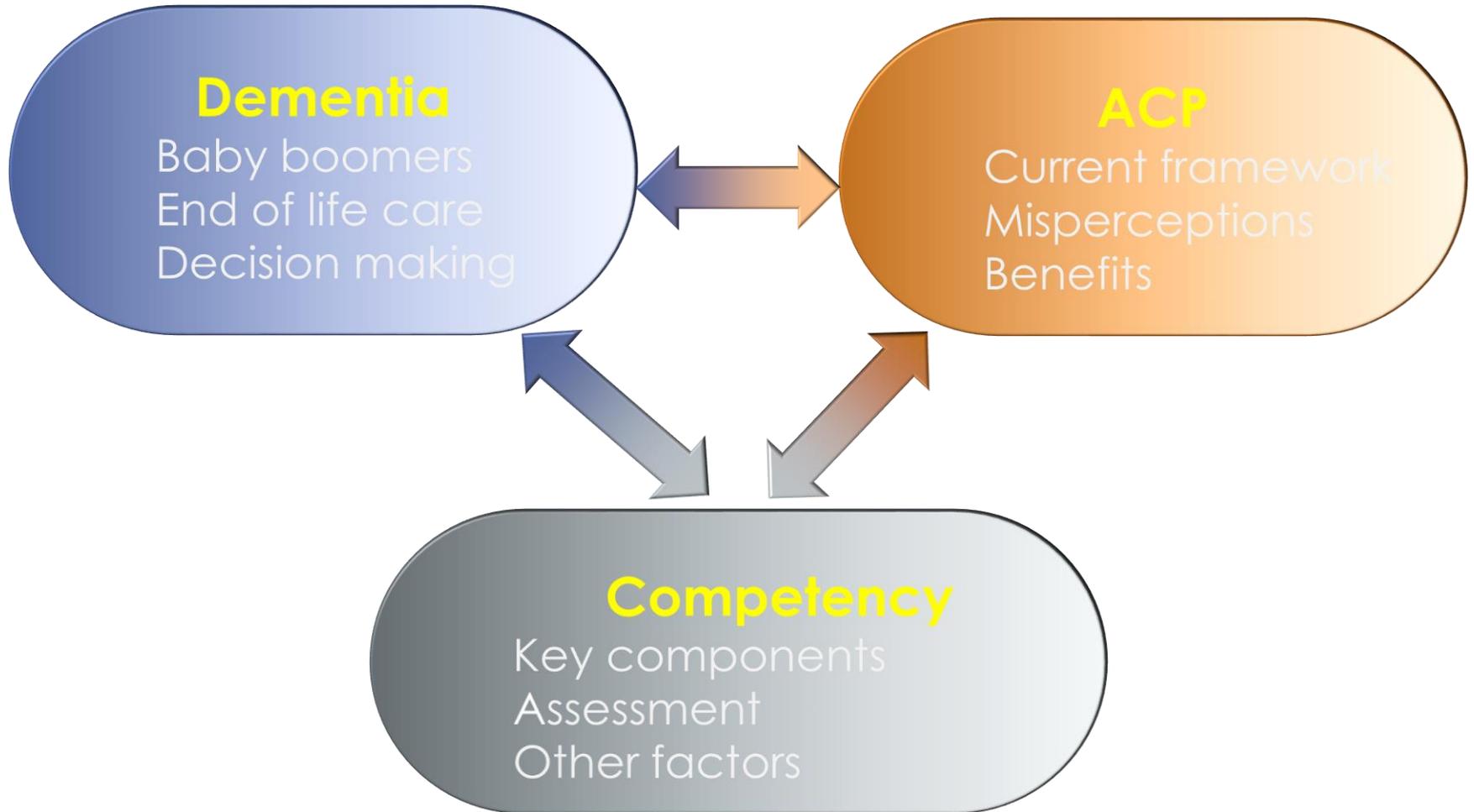
Geriatrician and Palliative Care Physician

February 2014



*"Honestly, I preferred when we
didn't talk about the elephant"*

Outline for Today



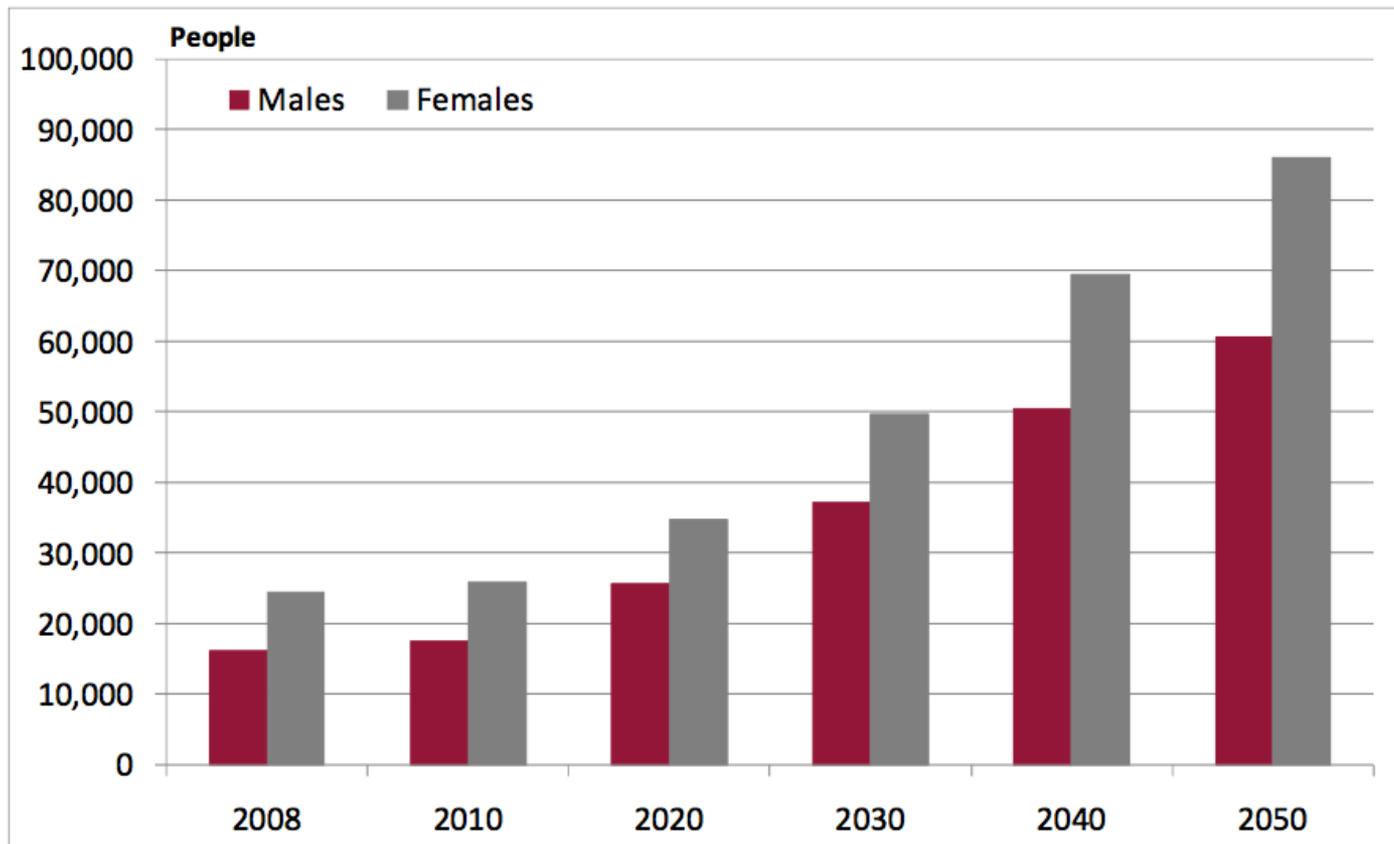
The Baby Boomers

- ▣ Retirement threshold reached in 2012
- ▣ Unique in many ways
 - ▣ Greater health literacy
 - ▣ Better resourced socially and financially
 - ▣ Contemporary social attitudes
 - ▣ Different family and social networks



NZ Dementia Survey

PREVALENCE PROJECTIONS BY GENDER, 2008 TO 2050



Poor EOLC in Dementia

- When compared with cancer:
 - More aggressive interventions despite similar preferences
 - Higher rates of unmet needs and untreated symptoms
 - Experience greater suffering
 - Overall poorer quality of life
 - Lower satisfaction with care



Barriers to EOLC in Dementia

- ▣ Lack of recognition as terminal illness
 - ▣ Disguised in death certificates
- ▣ Imprecise prognostication
 - ▣ Difficult to differentiate reversible downturns from terminal events
- ▣ Lack of communication



Decision Making in Dementia

- ▣ Current legal hierarchy of authority
 - ▣ Advance directive (?ACP)
 - ▣ Enduring Power of Attorney
 - ▣ Right 7 (4)
- ▣ Ethical standard of substituted judgment
 - ▣ Trying to discern or **guess** what the patient would have decided were they capable of doing so



Substituted Judgment

- ▣ Patients
 - ▣ Majority **assume** surrogates know their wishes
- ▣ Family surrogates
 - ▣ As likely to guess right as flipping a coin
 - ▣ Use standard of “best interests”
 - ▣ **Don't** revise decisions when informed
- ▣ Doctors
 - ▣ Under-rate QOL c.f. patients themselves
 - ▣ Do change when informed



Ethical Basis of ACP

- ▣ Future decision making
 - ▣ Precedent autonomy
- ▣ Thought experiment: *“Is a competent self able to make decisions for their future incompetent self?”*
 - ▣ **Yes:** one’s ownership of their ‘body’ is inviolable
 - ▣ **No:** dementia changes personhood so as to invalidate past decisions



Definition of ACP

- ACP is a *process of discussion* and *shared planning* for future healthcare. It involves an individual, whanau and health professionals.
- ACP gives people the opportunity to develop and express *their* preferences for future care based on:
 - Their values, beliefs, concerns, hopes and goals
 - A better understanding of their current and future health
 - The treatment and care options available



Differentiating ACP from AD

ACP

- Broad based
- Open to interpretation
- Deals with the **why**
- Dependent on HP
- Plans

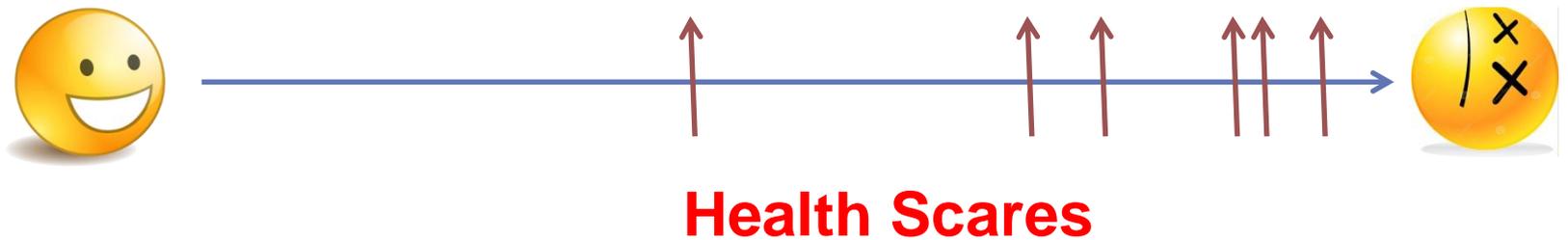
AD

- Specific and narrow
- Closed to interpretation
- Deals with the **what**
- Independent of HP
- Procedures

Framework of ACP and AD



Framework of ACP and AD



Framework of ACP and AD

**ACP:
Values &
Believes**

**AD:
Health
Decisions**

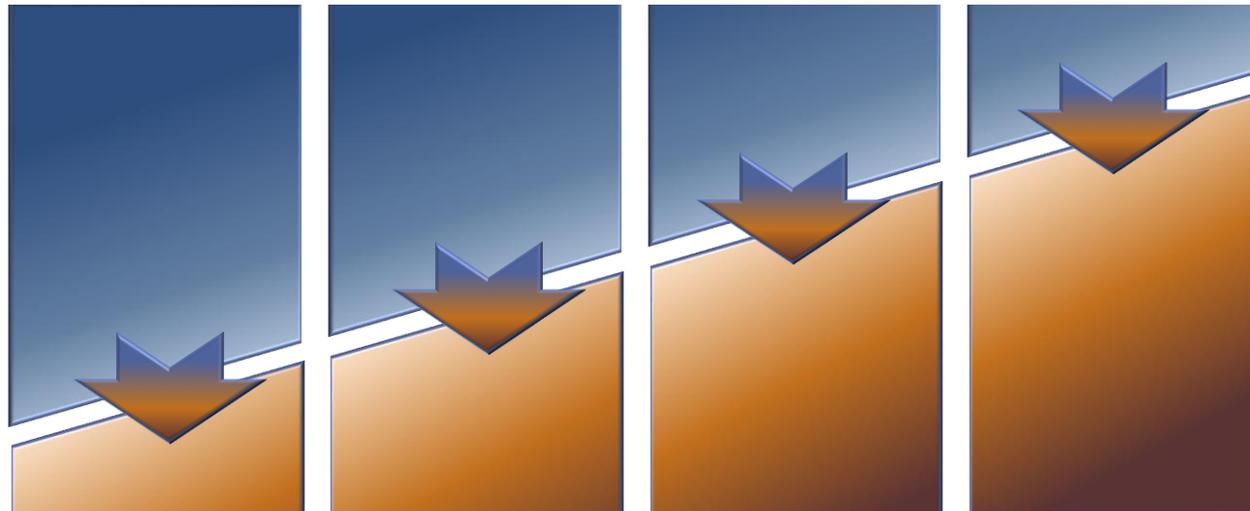


Health Scores

Framework of ACP and AD

ACP:
Values &
Believes

AD:
Health
Decisions



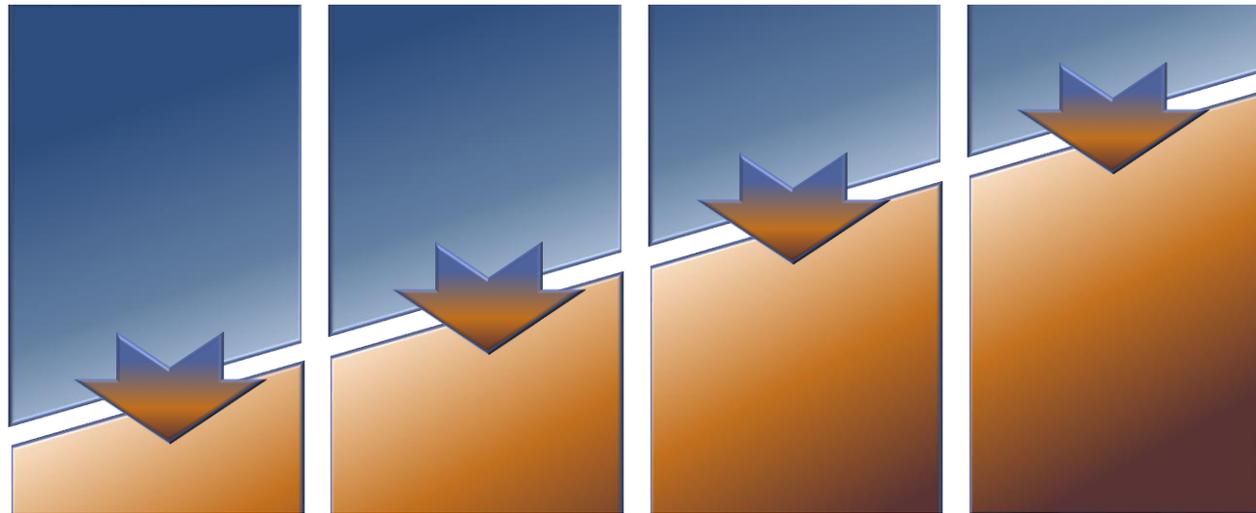
Health Scores

Framework of ACP and AD

Values remain stable thru life

ACP:
Values &
Believes

AD:
Health
Decisions



Preference sensitive decisions increase thru life



Health Scores

Q: When is the best time to ACP?



A: At Diagnosis of Dementia

- Dementia is unique in eroding capacity early
- ACP naturally located at diagnosis
- Learnings from “Breaking Bad News” in oncology
- Continued professional reluctance
 - Diagnostic uncertainty
 - Therapeutic futility
 - Presume patient and family against disclosure
 - Fear of negative psychological impact

Benefits of Communication and ACP

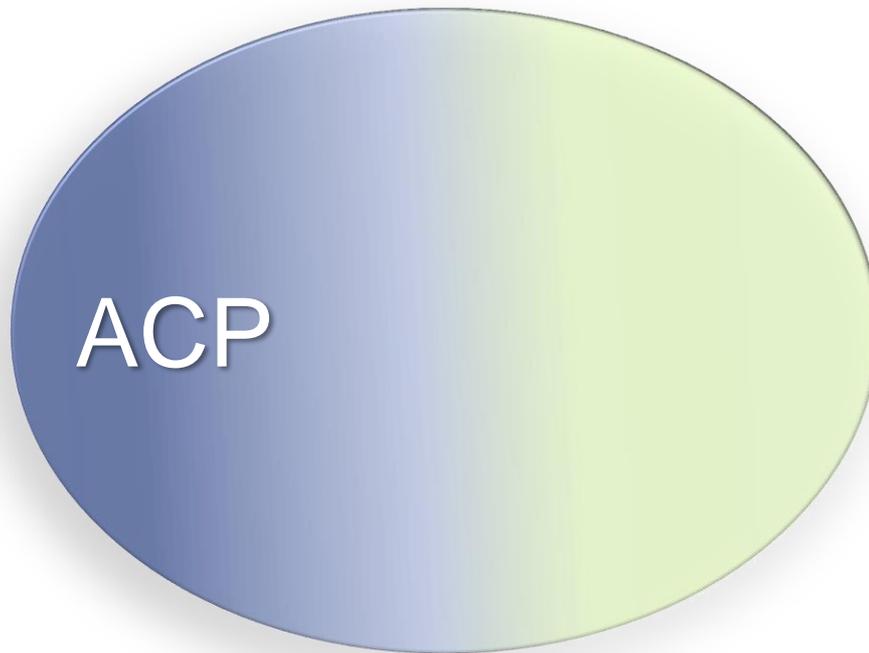
- ▣ **Fear**, isolation, confusion & **distress**
- ▣ Adherence to treatment and increased admissions
- ▣ **Quality of life** and **psychological morbidity**
- ▣ **Satisfaction** with care, complaints and litigation
- ▣ **Guilt**, confusion and **isolation in relatives**
- ▣ Burnout in healthcare professionals

The Clinical Conundrum

- ▣ ACP ensures patient centered EOLC
- ▣ People with dementia are excluded from ACP by their lack of competence

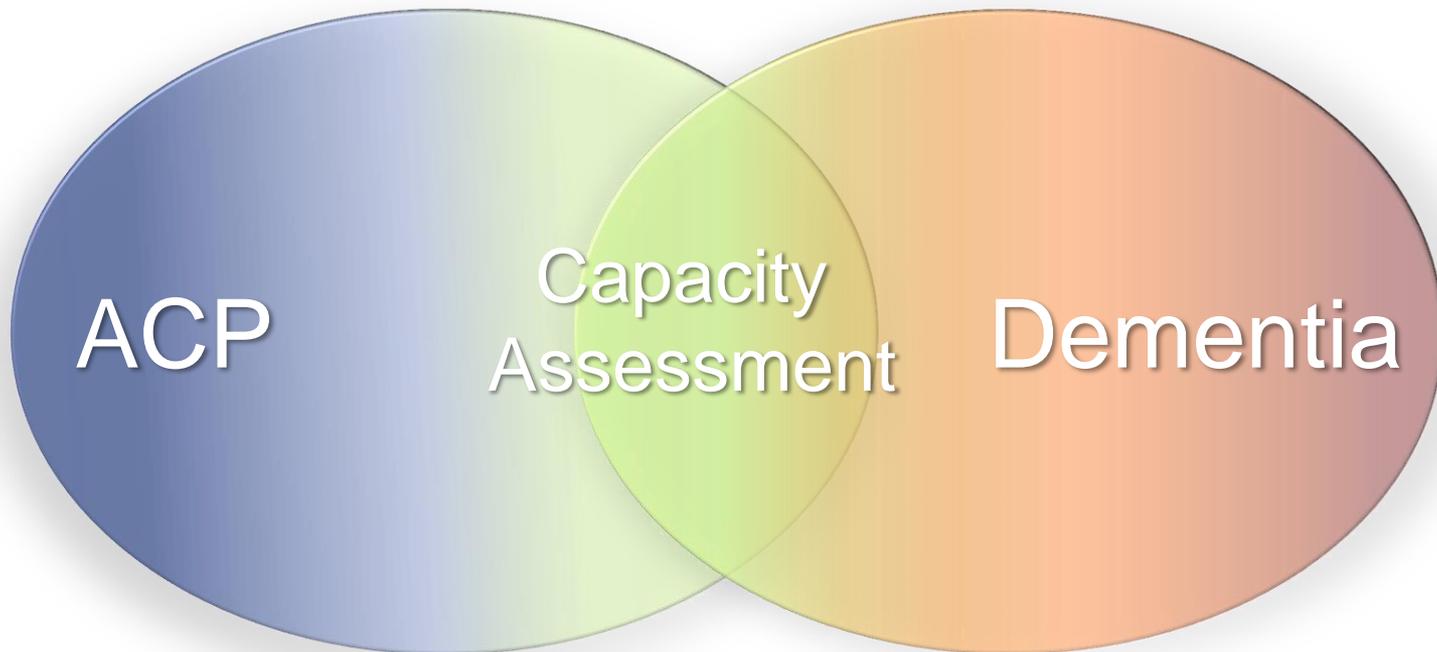
The Clinical Conundrum

- ▣ ACP ensures patient centered EOLC
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The Clinical Conundrum

- ▣ ACP ensures patient centered EOLC
- ▣ People with dementia are excluded from ACP by their lack of competence



Criteria for Competency

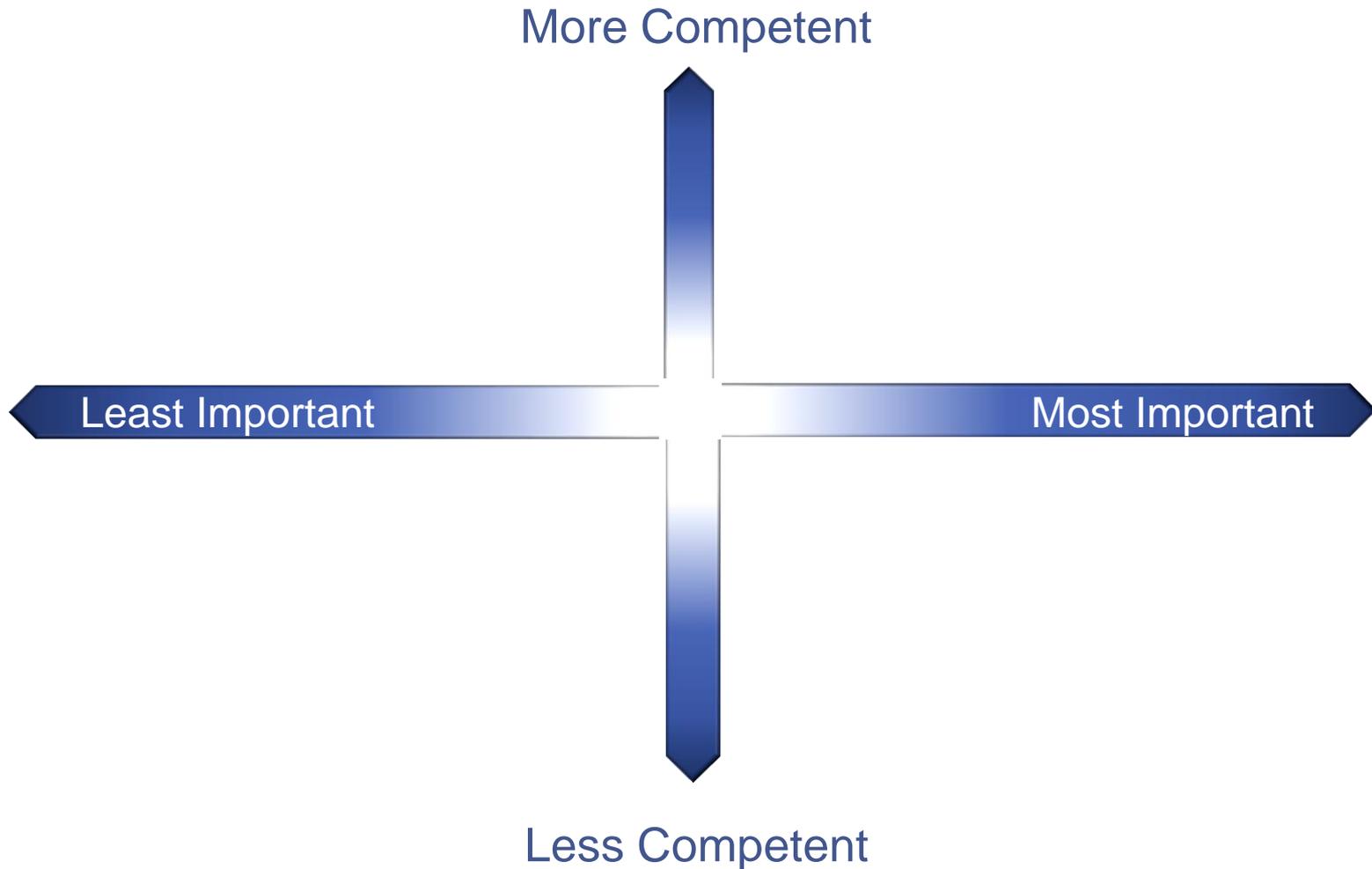
- ▶ Demonstrates an ability to **understand** the issues
- ▶ Shows an **appreciation** of how this information applies to oneself and the effects on their life
- ▶ Has an ability to outline their **reasoning** for their choices
- ▶ Has an ability to **communicate** their decisions voluntarily and without coercion

Parameters of Competence

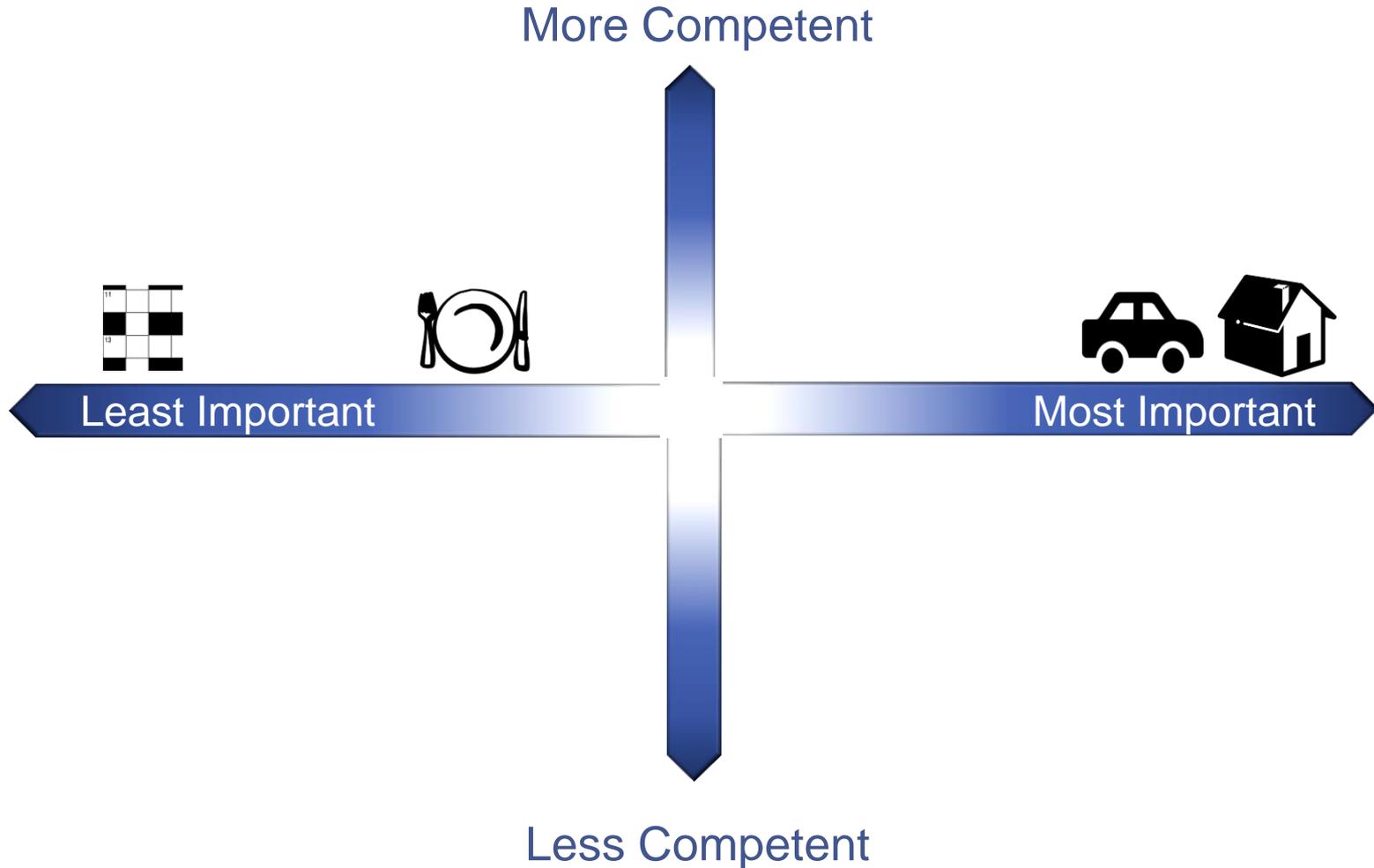
Least Important

Most Important

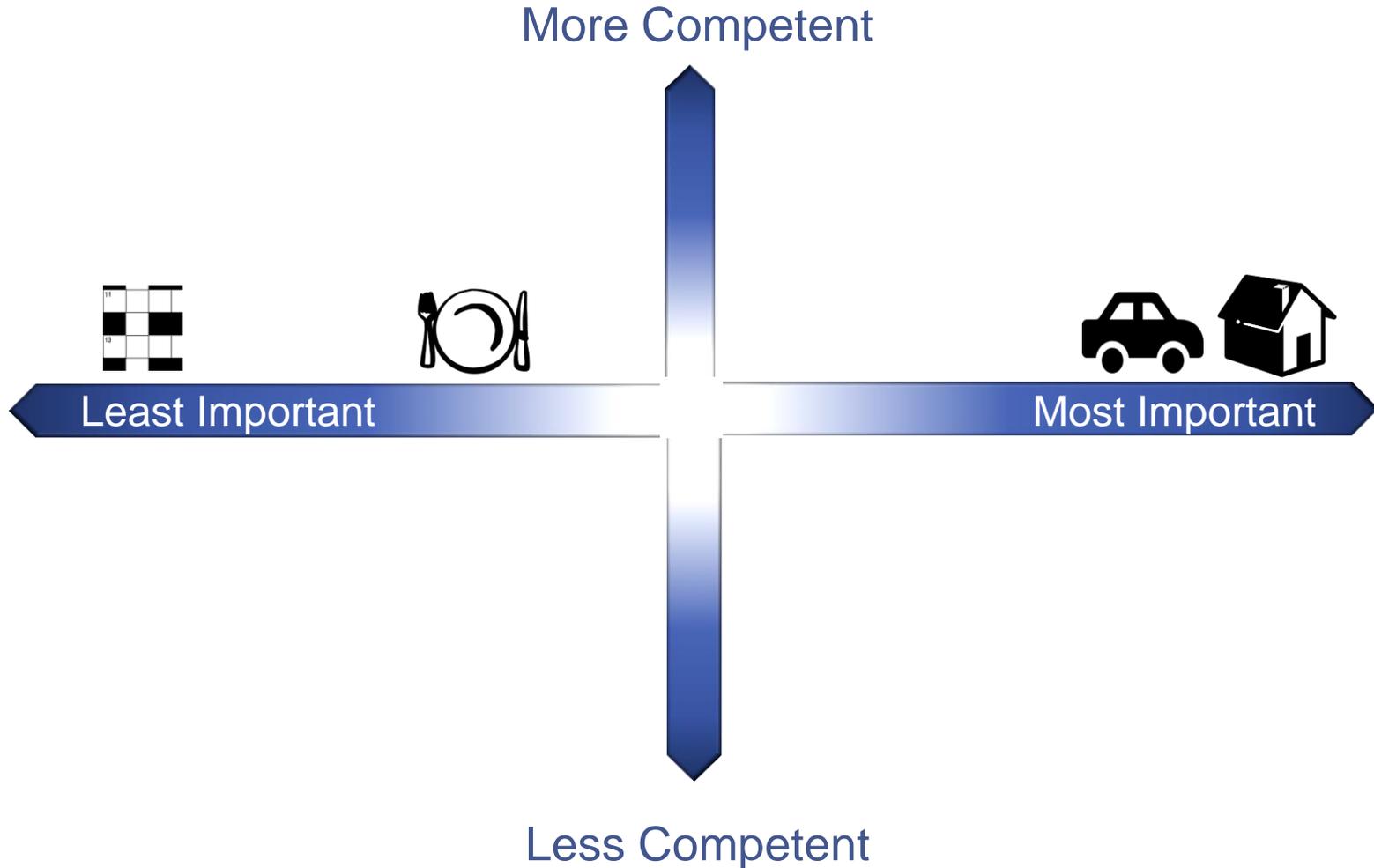
Parameters of Competence



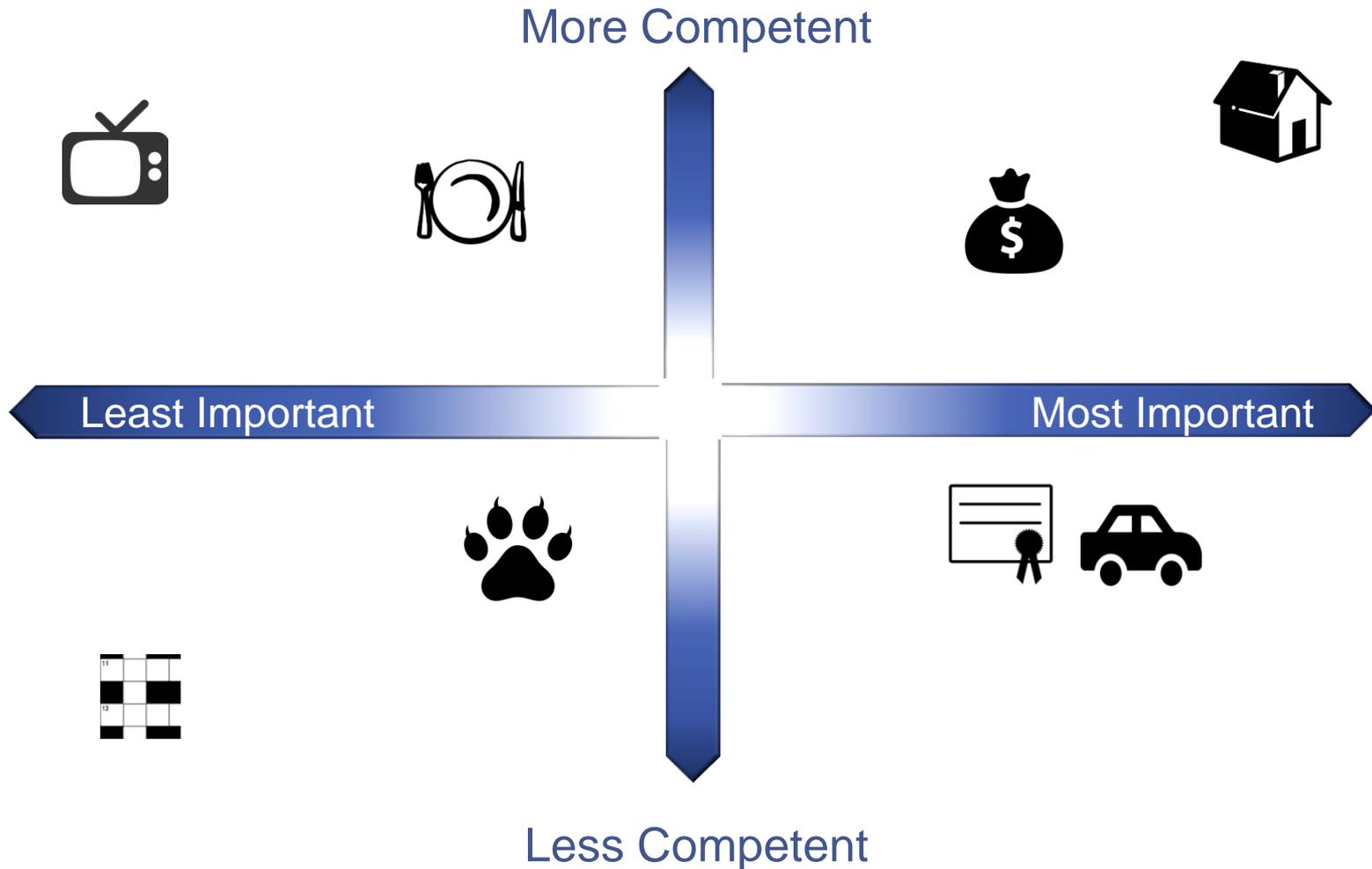
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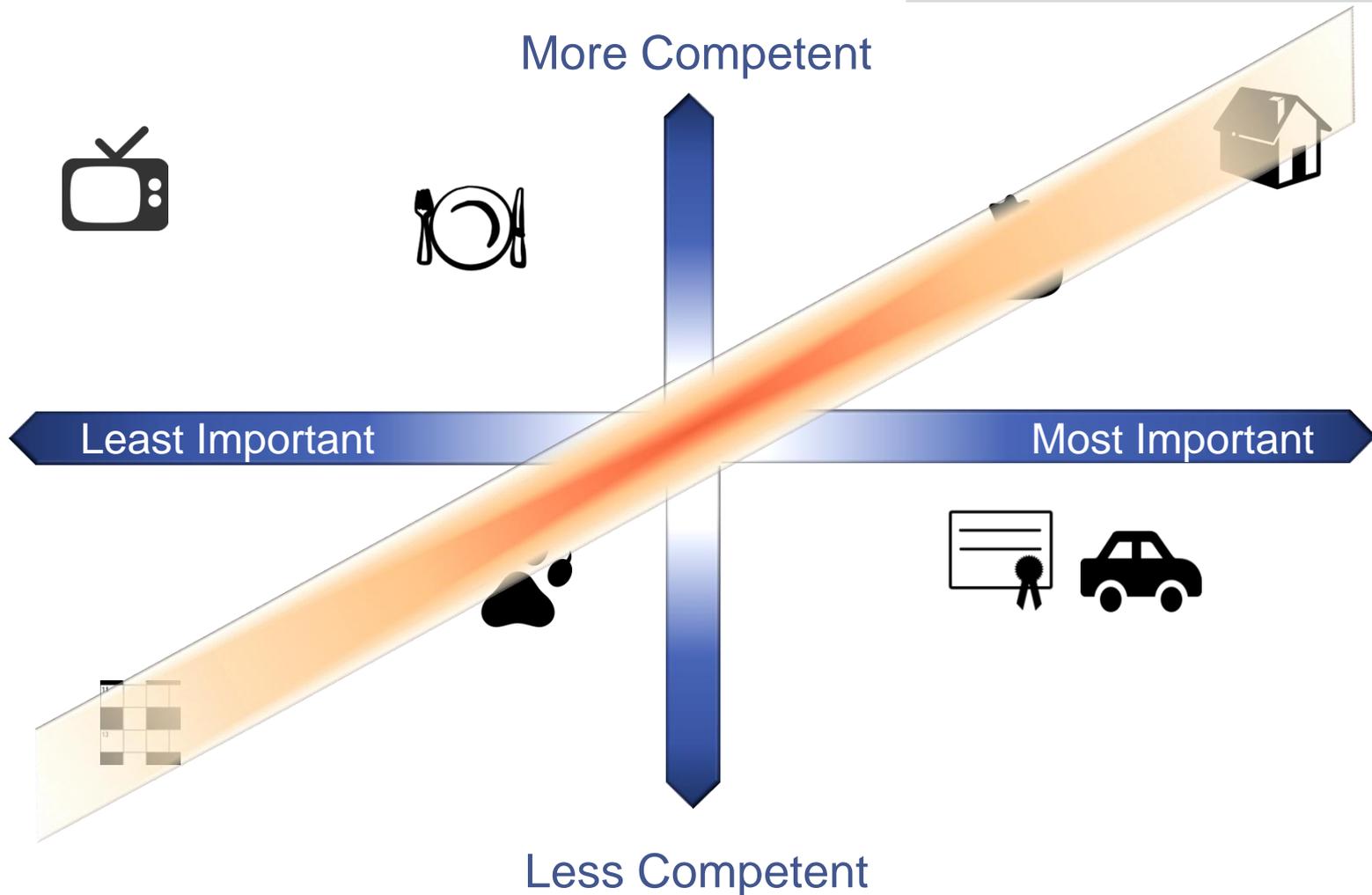
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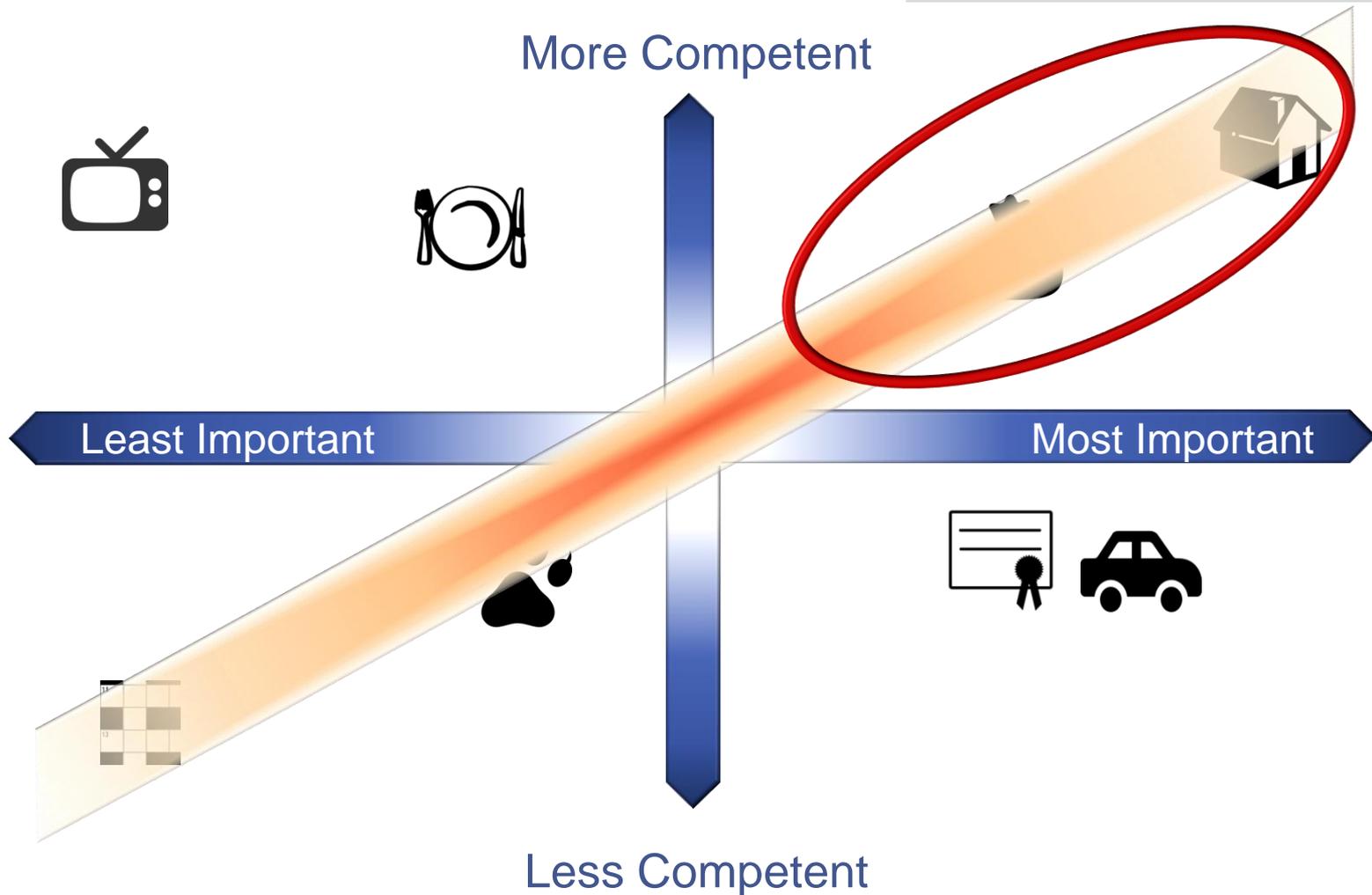
Parameters of Competence



Parameters of Competence



Parameters of Competence



Assessing Competency

- ▣ Expert clinical judgment
 - ▣ Subjectivity
 - ▣ Lack of formal training
 - ▣ Poor inter-rater reliability
 - ▣ Lack of standardisation
 - ▣ Conflict of role (physician assessor and carer)
 - ▣ Assumption that cognitive impairment = incompetence
- ▣ Structured clinical assessment
 - ▣ MacArthur Competency Assessment for Treatment (Mac-CAT)
 - ▣ Enhances, not replaces expert opinion

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ERR. 158/1.

Certificate of treatment

11/9/2009
This is to certify Maxwell Sanofi
Was treated on 11 Sept 09
Suffering from Headache (Stress)
Onset of their illness is He is thinking too much
He/she is fit to return to work on 3 Oct 09

Thank you
Yours faithfully
Sgd: [Signature]

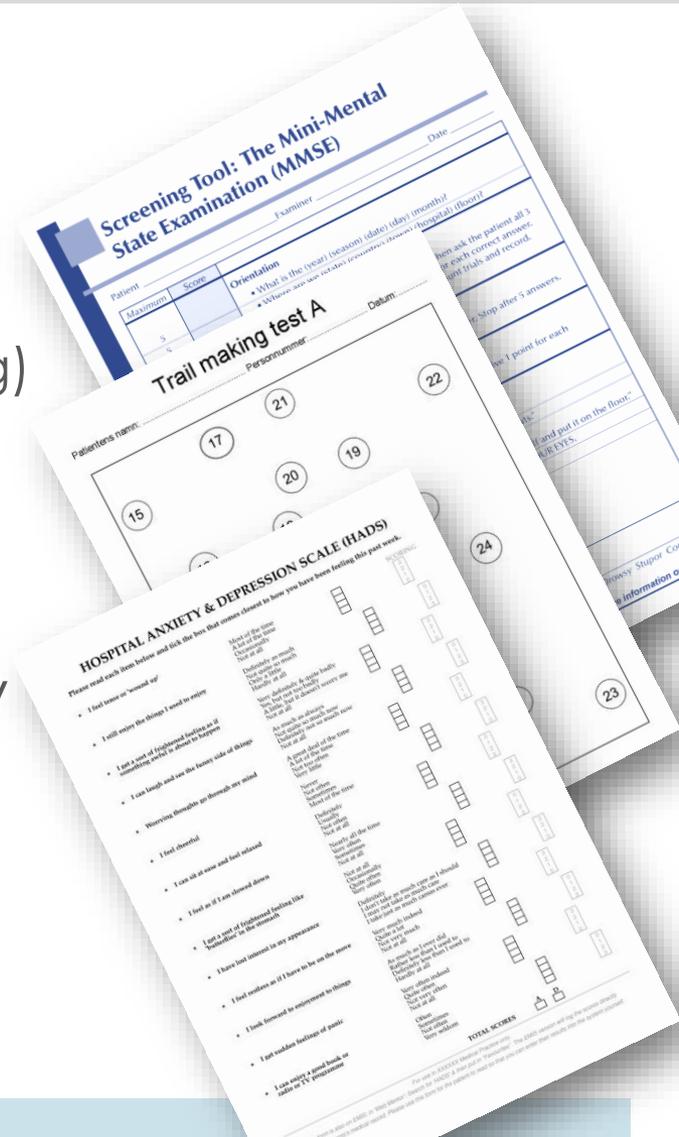
Dr. Maxwell Sanofi
MBBS, FCPS., (Gyne)
Assistant Professor
North Shropshire Medical College
EJ312AC

Assessing Competence in ACP

- ▣ Vignette method
 - ▣ Don't involve a great degree of cognitive processing
 - ▣ Importance of relevancy of scenarios
 - ▣ Personally relevant
 - ▣ Generating an emotional reaction enhances appreciation of information

Other Contributing Factors

- Cognitive Screening tools
 - MMSE 18-25
 - Executive function screen (Trail scoring)
- Depression
- Family assessment of competency



Our Interests

- ▣ Provide assistance in the assessment of competency to engage in ACP discussions
- ▣ Standardised competency assessment tools:
 - ▣ ACP-CAS (structured clinical interview)
 - ▣ Adapted from Mac-CAT
 - ▣ ACP-CAV (vignette method)
 - ▣ 3 ACP scenarios used as the vignettes

Aims of Our Study

1. Compare ACP-CAP and ACP-CAV with an independent expert's opinion of capacity
2. Correlate these measures with:
 - Demographic data
 - Surrogates opinion of capacity (yes or no)
 - GDS
 - Cognitive screens:
 - ▣ MMSE
 - ▣ Trail making A & B

Participant Criteria

- ▣ Inclusion criteria:
 - ▣ All residents in Selwyn Village and St Andrews

- ▣ Exclusion criteria
 - ▣ Non-fluency in English
 - ▣ Unavailability of NOK/EPOA

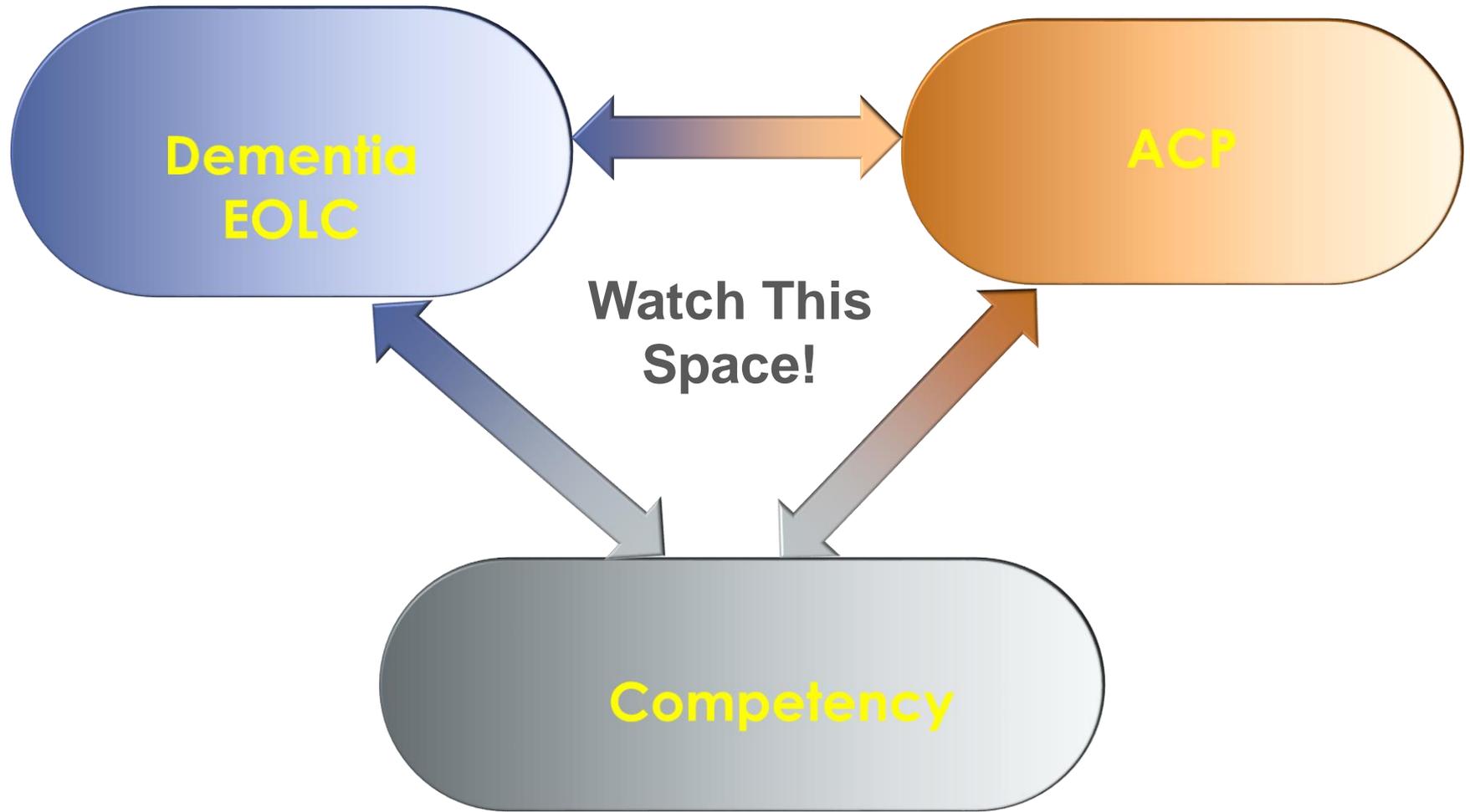
The Issue of Consent

- ▣ Participants capacity to provide informed consent was unknown:
 - ▣ Those with capacity can exercise informed consent
 - ▣ Those without capacity can exercise *assent* with informed consent provided by a surrogate
- ▣ Surrogate informed consent was thus needed for *all* participants

Assessment Process

- ▣ Coordinated and conducted by research assistant
 - ▣ 1-2 hrs to undertake each assessment
 - ▣ Comprised:
 - *ACP-CAV*, ACP-CAS*, videotaped for subsequent independent expert opinion
- 49 assessments completed and being analysed

Summary



Advance Care Planning (or ACP) is the process of thinking about, talking about and planning for future health care and end of life care.

Are you looking for information for:

Yourself?

A loved one?

Your patients?

www.advancecareplanning.org.nz

Acknowledgements

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