NIH Consensus Conference on Family History

Systematic family history collection in primary care populations: impact on health outcomes and factors affecting collection

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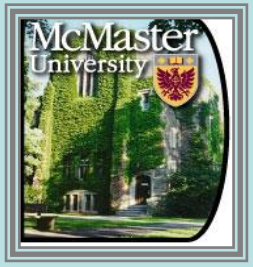

Acknowledgements

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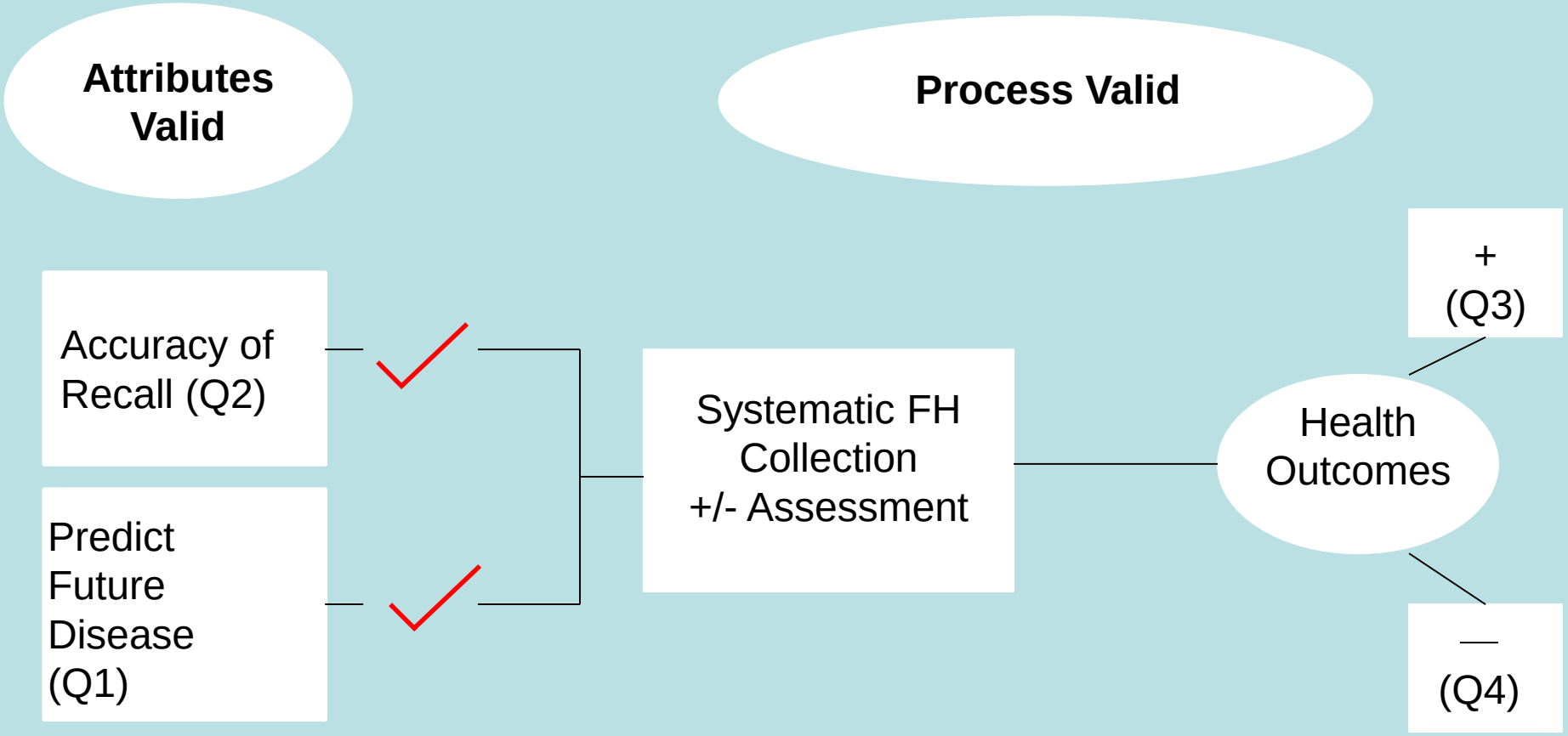
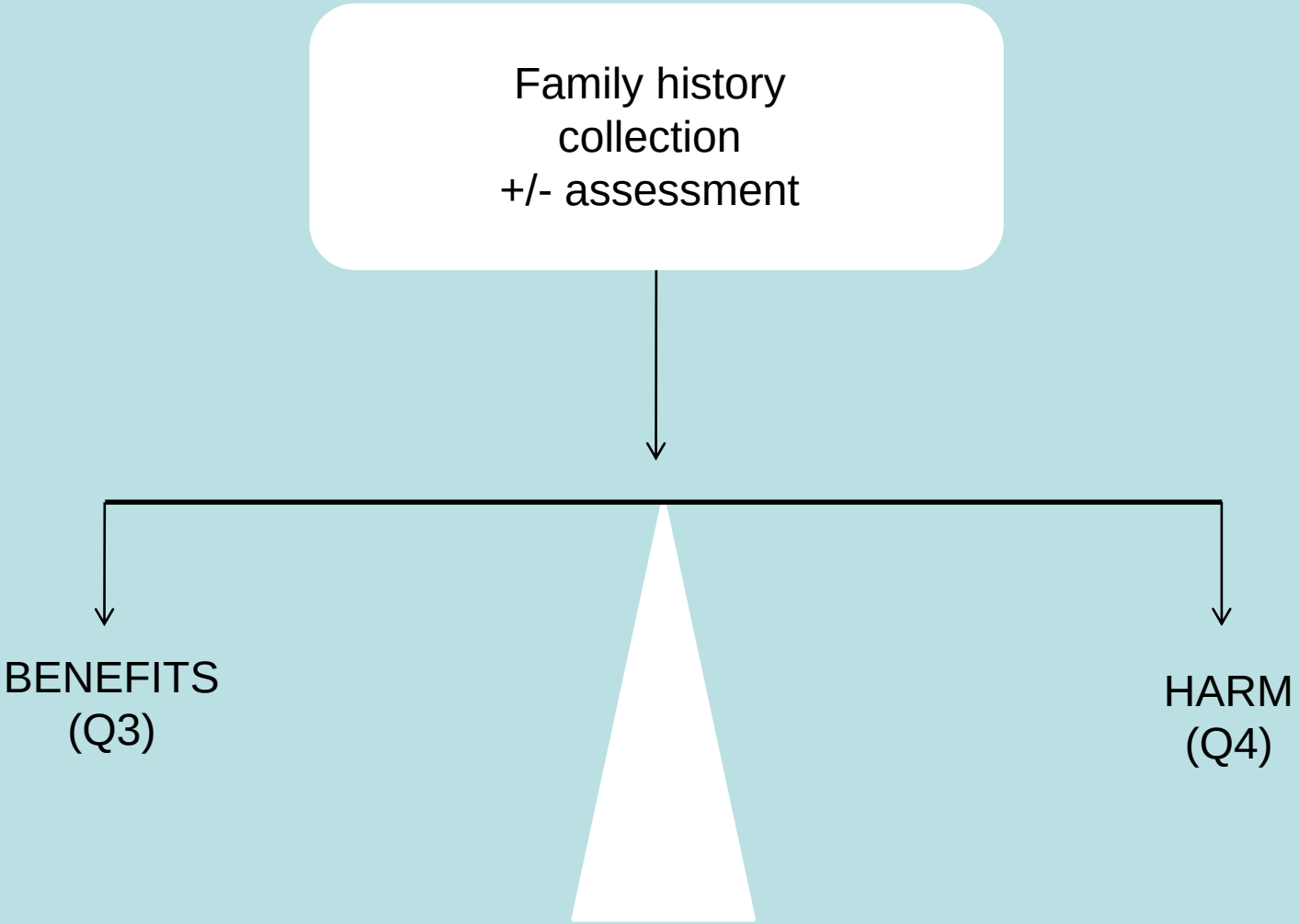
- Canadian Institutes of Health Research
- Ontario Women’s Health Council
- Agency for Healthcare Quality & Research

Evaluating the Family History in Primary Care

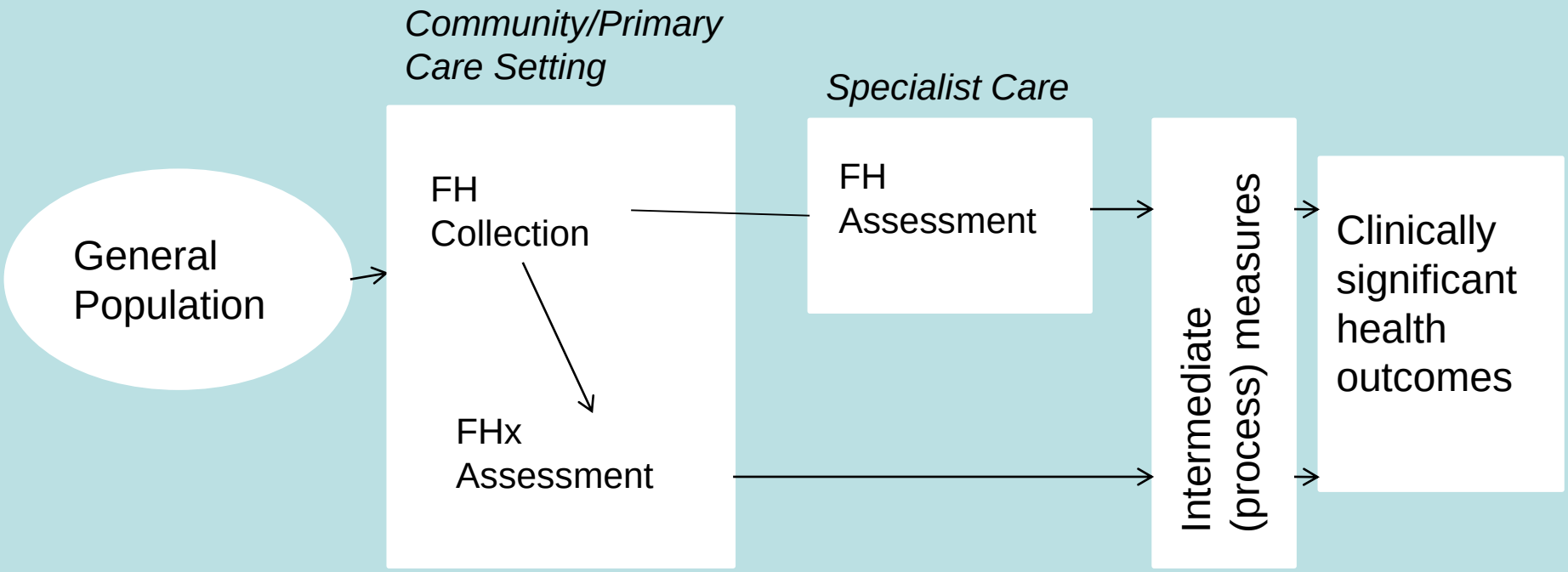



Family history
collection
+/- assessment
BENEFITS
(Q3)
HARM
(Q4)

U.S. Preventive Services Task Force Grades for Strength of Overall Evidence

Grade	Definition
Good	Evidence includes consistent results from well-designed, well-conducted studies in representative populations that directly assess effects on health outcomes.
Fair	Evidence is sufficient to determine effects on health outcomes, but the strength of the evidence is limited by the number, quality, or consistency of the individual studies; generalizability to routine practice; or indirect nature of the evidence on health outcomes.
Poor	Evidence is insufficient to assess the effects on health outcomes because of limited number or power of studies, important flaws in their design or conduct, gaps in the chain of evidence, or lack of information on important health outcomes.

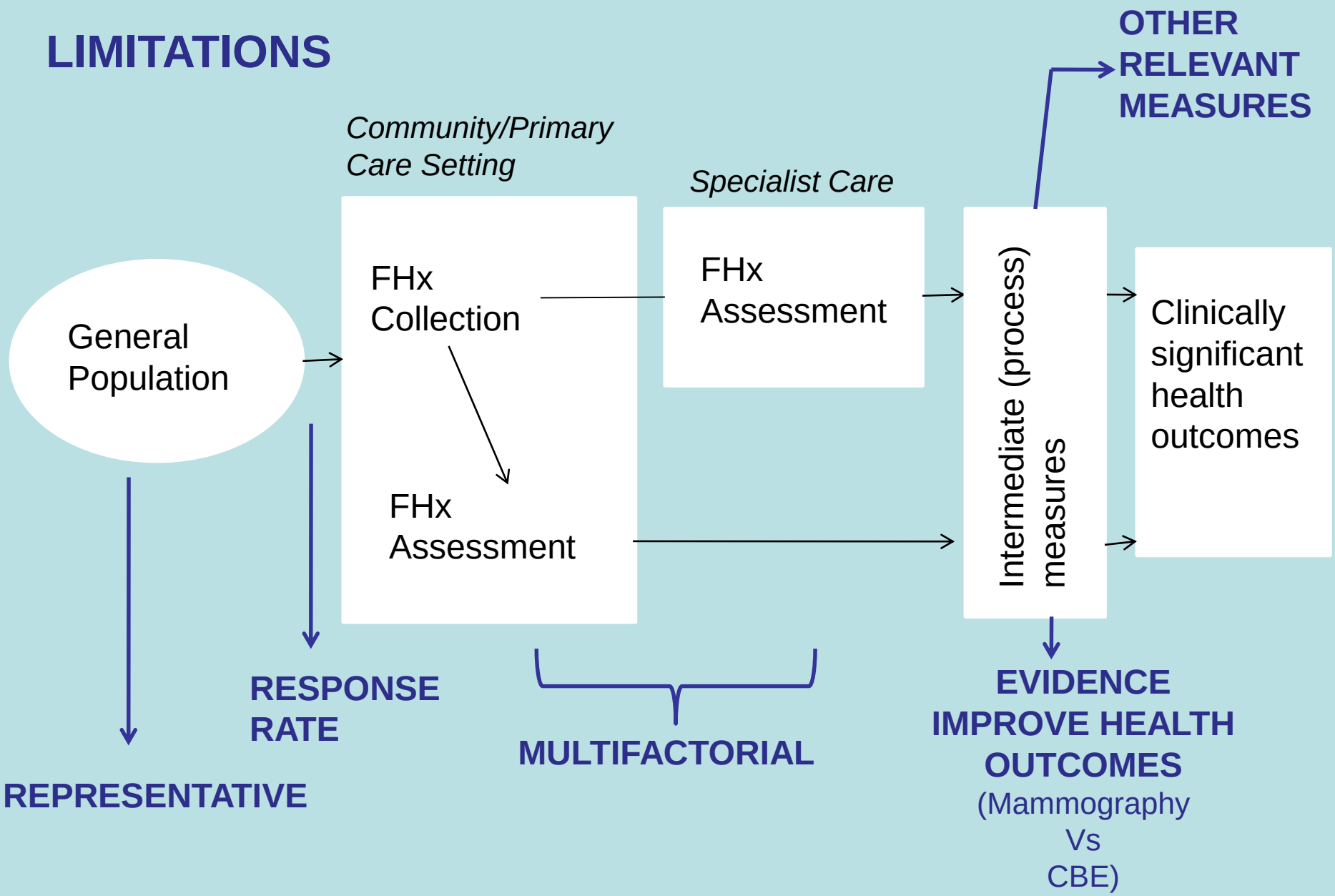
Direct evidence that family history will improve health outcomes (Q3)



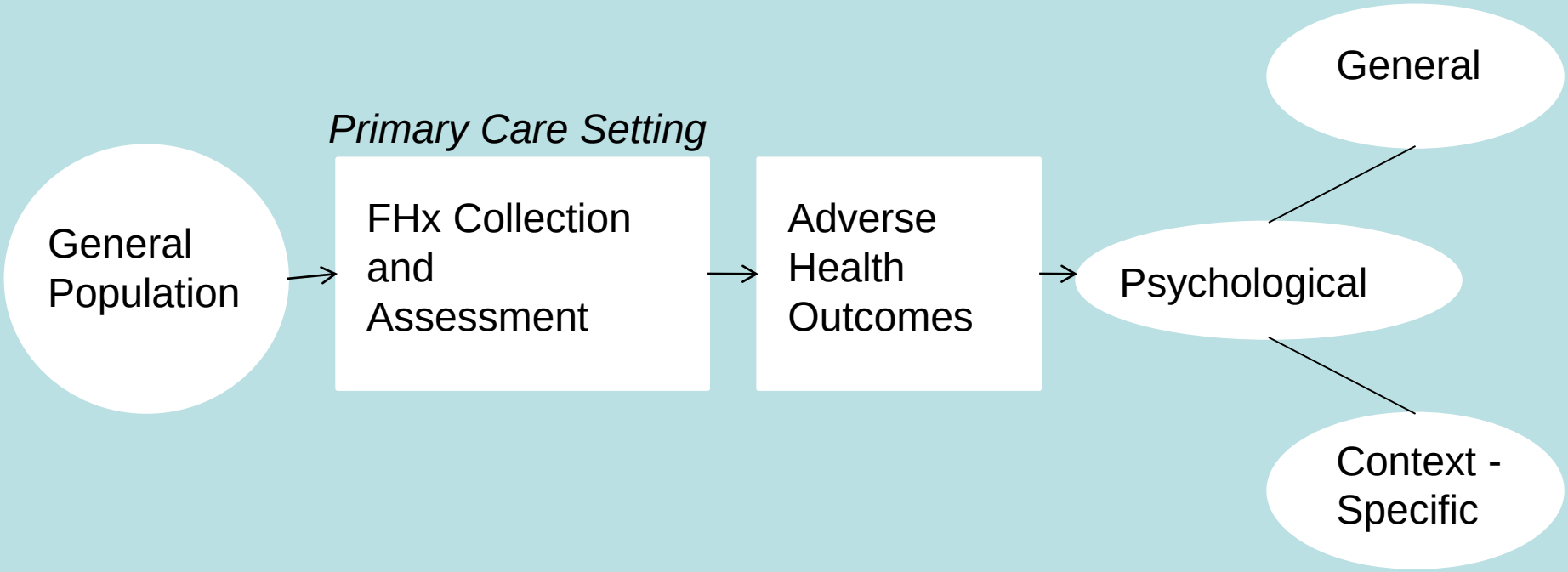
	Kadison, 1998	Giles, 2001
Design	Uncontrolled B&A	Uncontrolled B&A
Conditions	Breast/Ovarian	Breast/Ovarian
Recruitment and Setting	Email invitation Two large employers, Boston, MA, U.S.	Walk in Community pharmacies and health screening event, Richmond, VA, U.S.
Population	Female employees	Women ≥18y
FHx intervention	Telephone-administered survey	Interviewer-administered survey
Who delivered	Automated telephone based Breast Cancer Risk Assessment System with option of paper copy	Community Pharmacist
Target Behaviour	Screening mammography CBE BSE	Screening mammography CBE BSE
Outcome measure	Adherence to recommendations	Adherence to recommendations

	Kadison, 1998 [%]	**Giles, 2001 [%(95% CI)]**
No. analyzed/ No. allocated Follow-up period	136/343 [39.7%] 8 months	140/188 [74.5%] 6 months
Adherence to **mammography**	Pre: 22/29 [76%] Post: 27/29 [93%] P<0.0572	**≥50y** Pre: 33/44 [75% (62-88)] Post: 31/44 [70% (57-84)] P<0.48 **40-49y** Pre: 18/32 [56% (39-73)] Post: 21/32 [66% (49-82)] P<0.257
Adherence to **Clinical Breast Examination** (CBE)	Pre: 98/119 [82%] Post: 110/119 [92%] P<0.0137	Pre: 121/140 [86% (81-92)] Post: 128/140 [91% (87-96)] P<0.09
Adherence to **Breast Self Examination** (BSE)	Pre: 40/119 [34%] Post: 74/119 [62%] P<0.001	Pre: 42/137 [31% (23-38)] Post: 77/137 [56% (48-64)] P<0.001

Direct Evidence Q3



Direct evidence that family history leads to adverse health outcomes (Q4)

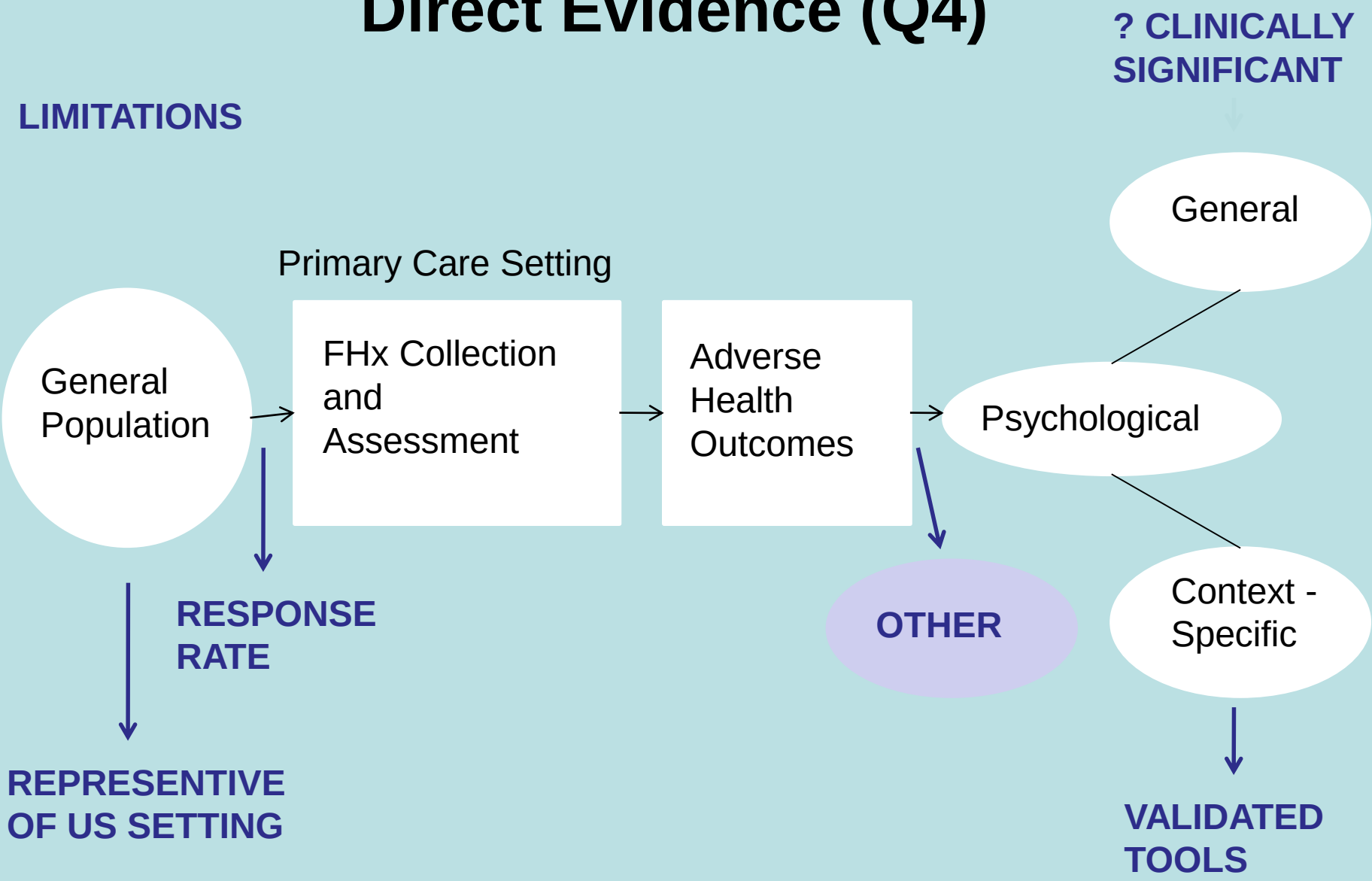


	Leggatt, 2000	Qureshi, 2001	Rose, 1999
Design	Uncontrolled B&A	RCT	Uncontrolled B&A
Conditions	Colorectal/Breast cancer	Generic	Generic
Recruitment and Setting	Postal survey. Single family doctors office, UK	Invited to PHE. Single family doctors office, UK	Invited to clinic. Single family doctors office, UK
Population	Unselected aged 35 to 65	Random selection aged 18 to 60	Patients aged 20 to 34
FHx intervention	Cancer FH collected by postal survey	In-office self-administered FH questionnaire	Three generation FH recorded on proforma in clinic
Who delivered	Lower risk group: letter from family doctor. Potentially increased risk groups: family doctor and/or oncologist/geneticist	Medically trained researcher. Results reviewed by family doctor +/- clinical geneticist	GP and health visitor
Outcome measure;	SF-STAI CWS	SF-STAI Perception of Health PCQ (FH concern)	SF-STAI
Timing of measure	Baseline, 4-6w	Baseline, 1w, 2w, 3m	B & A clinic , 12 w

	Legatt, 2000	Qureshi, 2001	Rose, 1999
No. analyzed/ No. allocated	Intervention: 666/568 (85%)	Intervention: 34/50 (68%) Control: 42/50 (84%)	Intervention: 91/124 (73%)
Anxiety outcomes, (SF-STAI)	Mean **Lower risk** (n=427) Pre: 35.8; Post (4-6w): 35.1 **False positive (n=7)** Pre: 34.8 Post (4-6w): 34.3 **Higher risk (n=18)** Pre: 36.3; Post (4-6w): 38.9	Mean **Intervention** Pre: 36.7; Post (1w): 39.4; Post (2w): 37.1; Post (3m): 34.2 **Control** Pre: 36.4; Post (1w): 33.0; Post (2w): 32.5; Post (3m): 34.8 p=0.0014	Mean Pre: 38.4 ; Post (immediate): 30.1 ; Post (12w): 33.0 Pre v post (immediate), p<0.001

	Legatt, 2000	Qureshi, 2001
Other outcomes	**Cancer Worries Scale** ***Perception of own chances of developing cancer*** Mean **Lower risk** (n=534) Pre: 2.95; Post (4-6w): 2.83 **False positive** (n=11) **Pre: 3.55 ;** **Post (4-6w): 3.27** **Higher risk** (n=25) **Pre: 3.56 ;** **Post (4-6w): 3.40**	**Perception of Health Questionnaire** ***Risk of developing something wrong in the future item:*** More negative response from pre to post (1week) Intervention 26% vs Control 7% (p=0.025) **Psychological Consequence Questionnaire (for FH concerns)** Post (2weeks) Intervention vs Control (p=0.67) Post (3 months) Intervention vs Control (p=0.25)

Direct Evidence (Q4)



Factors that encourage or discourage obtaining and using a family history (Q5)

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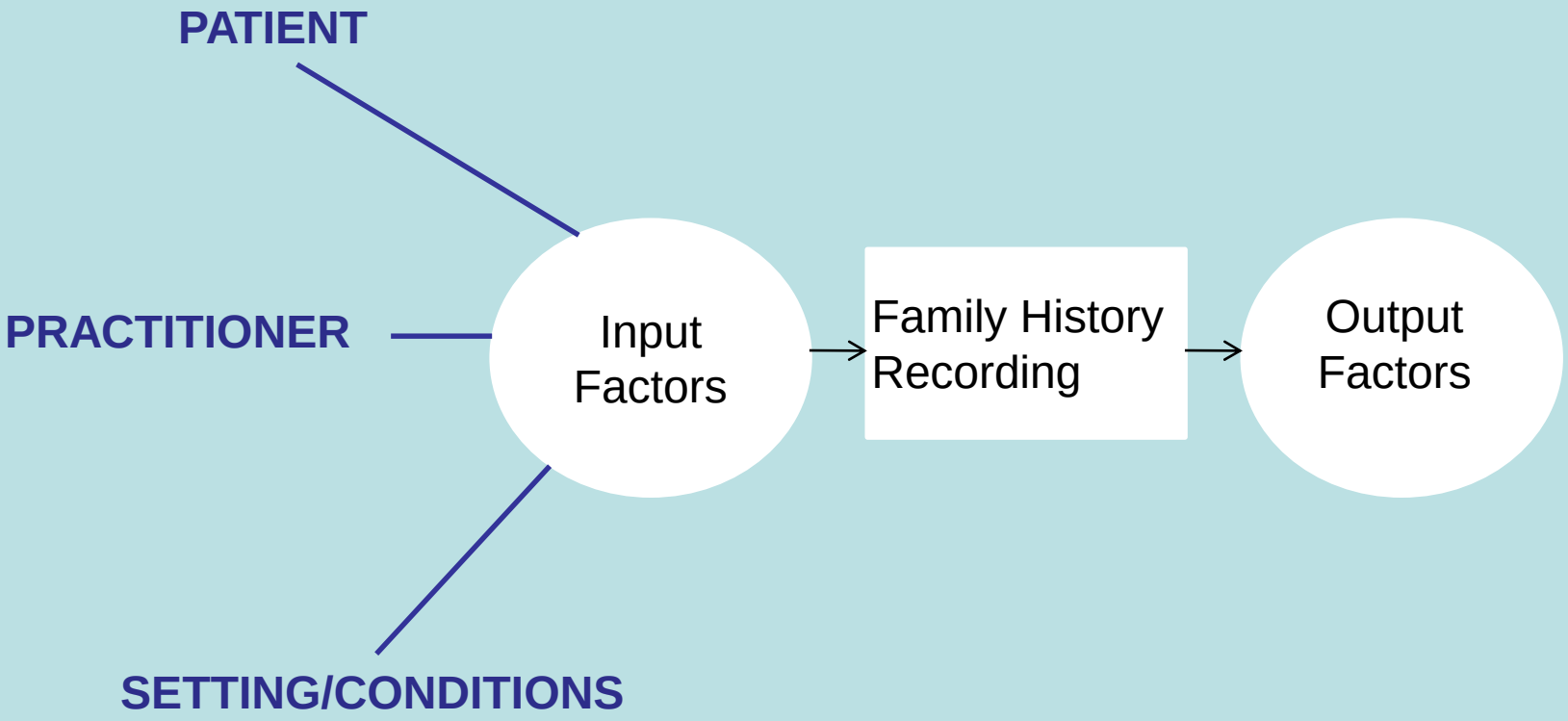
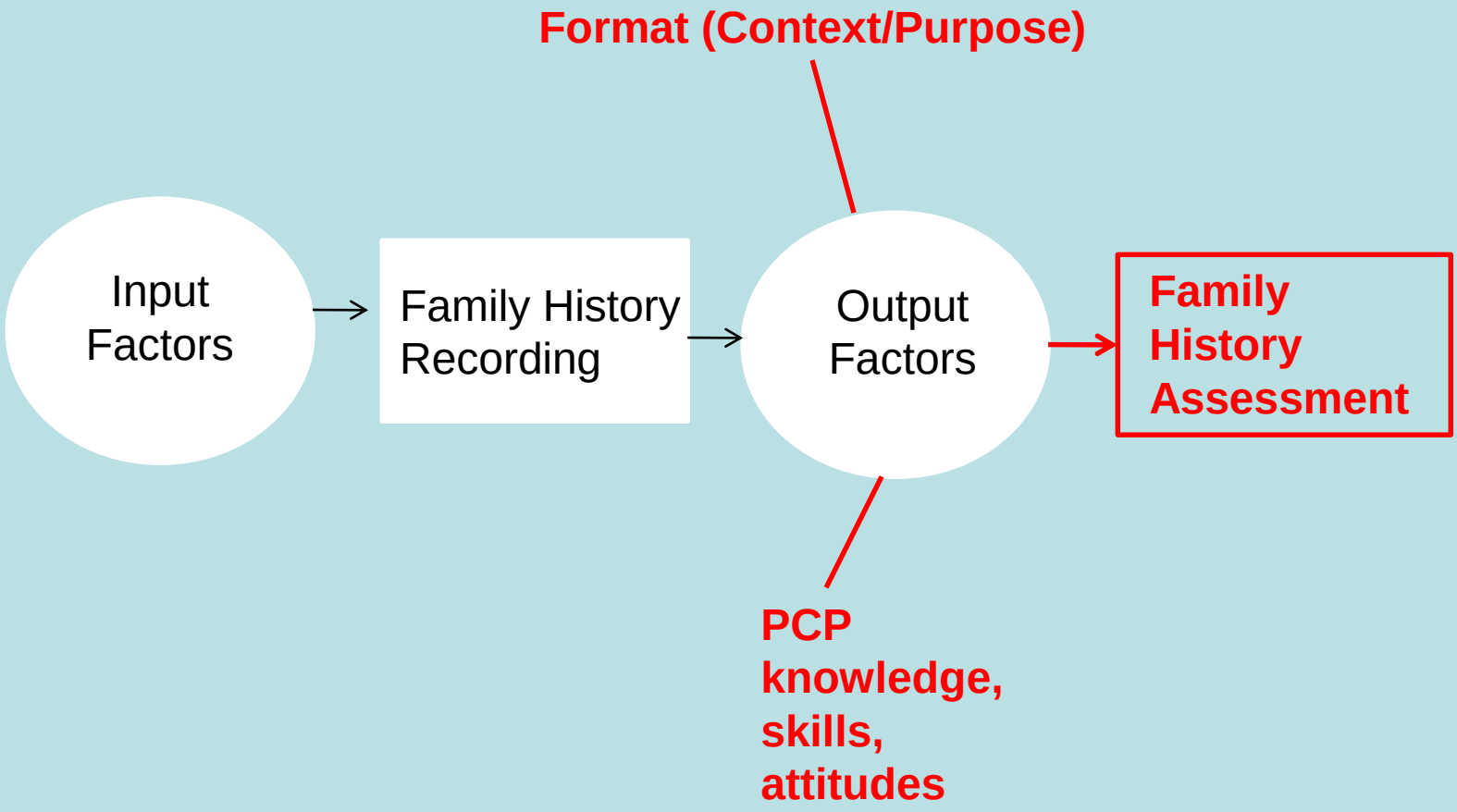


Factors associated with improved FH recording

	Improved FH Collection in Medical Records	Clinician discussing FH	Improved self-reporting of FH (not accuracy)
Patient factors	White (non-Hispanic) Certain medical conditions	Not on state health insurance Patients who worry about breast cancer Age: mixed picture	Women White non-Hispanics Higher education status Certain common cancers
Practitioner factors		Established clinician Resident trained	
Setting		Routine physical examination	

Factors that encourage or discourage obtaining and using a family history



“Collectively genetic diseases are not rare nor do they any longer justify automatic pessimism provided doctors are reasonably well informed. Professional ignorance, may, however, be the greatest obstacle…..”

Rodney Harris, 1991
Emeritus Professor of Medical Genetics
University of Manchester

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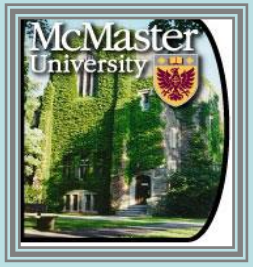
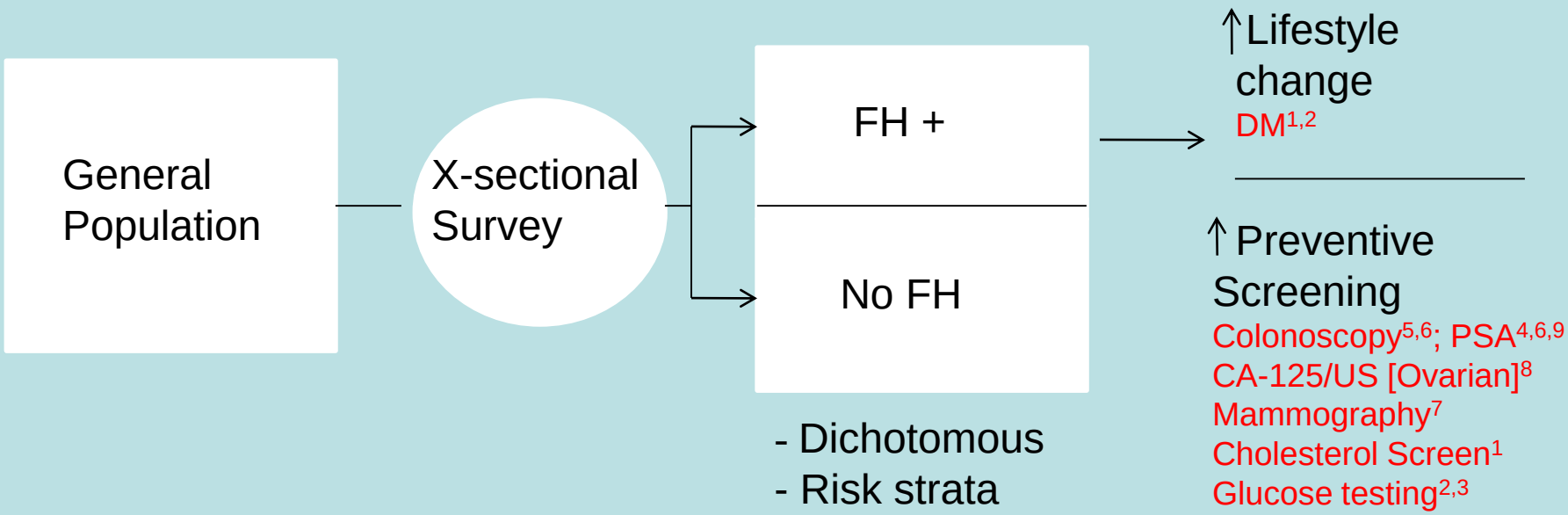
Supplementary slides

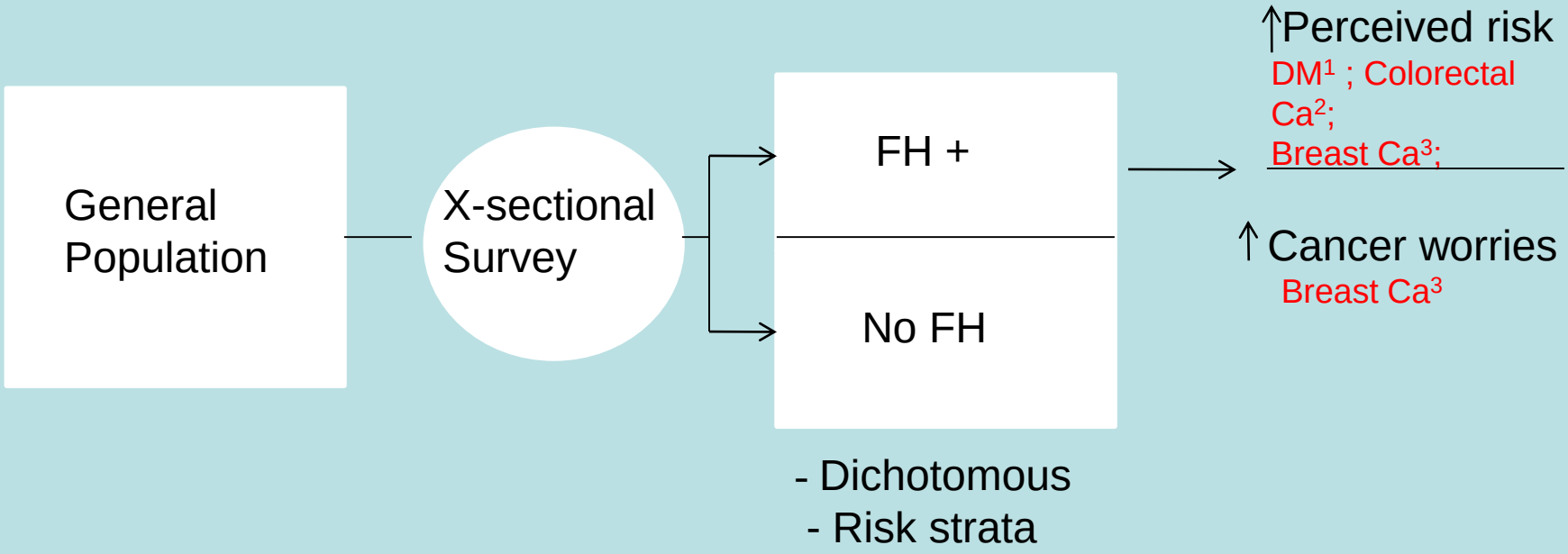


Indirect Evidence Q3



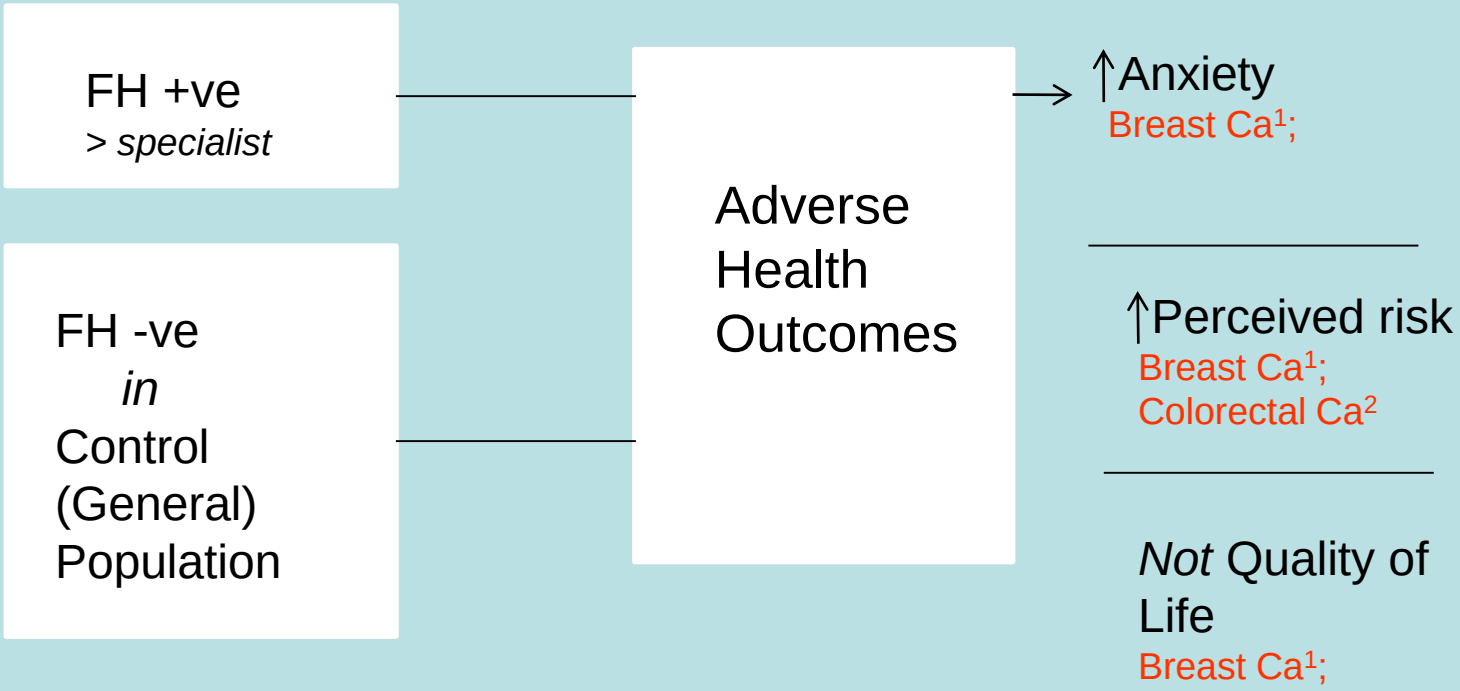
1. Zlot et al. 2009; 2. Qureshi et al. 2007; 3. Murff et al 2004; 4. Jacobsen et al 2004; 5. Longacre et al. 2006; 6. Shah et al 2007; 7. Williams et al 2008; 8. Anderson et al. 2002; 9. Broom et al. 2006

Indirect Evidence Q4



1. Zlot et al. 2009; 2. Longacre et al. 2006; 3. Anderson et al. 2002 ; 4. Broom et al. 2006

Indirect Evidence Q4



1. Gil et al. 2006; 2. Jacobsen et al. 2004