CONSUMER HEALTH INFORMATION REVOLUTION

Jim Warren

ACHI Foundation Fellow

Professor of Health Informatics, School of Computer Science, University of Auckland

THE UNIVERSITY OF AUCKLAND
FACULTY OF SCIENCE

Healthcare: 'The system'

- The people and organisations that identify as being in the healthcare sector
  - Hospital, clinics, home visiting services and back-end support (public health, admin)
  - Providers at the point of care
    - Doctors (GPs, specialist physicians, surgeons)
    - Nurses, pharmacists, physios, OTs, social workers
  - Coordinators and administrators
    - More doctors (public health physicians, department heads, CMOs)
    - Other managers (CFO, CIO, CEO, practice managers)
- Delivering high-quality healthcare is their job

Healthcare: the ‘patient’ (or consumer)

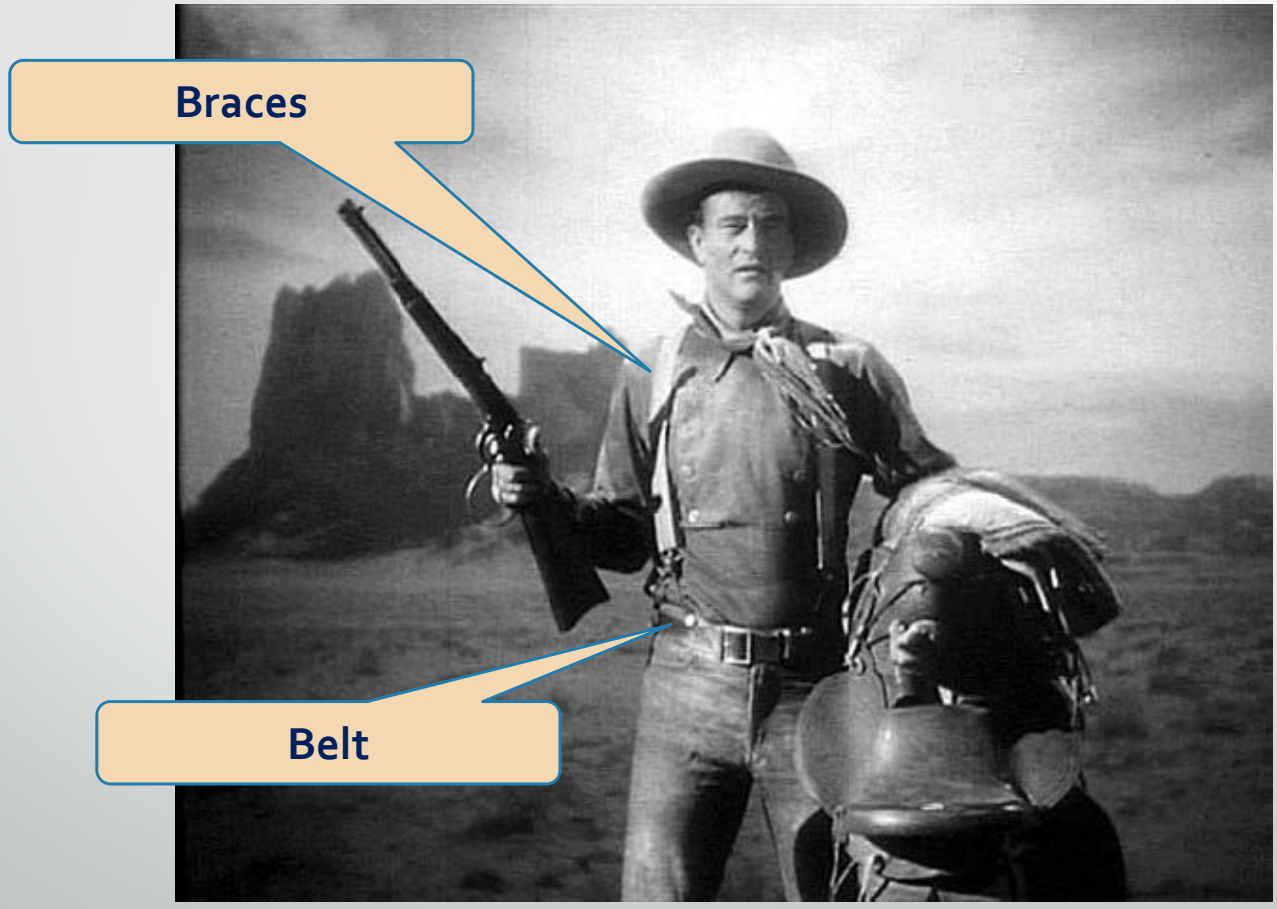
- Patients
  - Individuals under the care of a healthcare professionals who are working for ‘the system’
- Health consumers
  - The same people, but emphasising their decision-making agency
  - People thinking about engaging the system
- Support people
  - Spouse, other family members / whānau
  - Volunteers or professionals acting for the patient
  - People in the same room with the patient at the point of care
  - People who help the patient reason about their condition

Chronic conditions

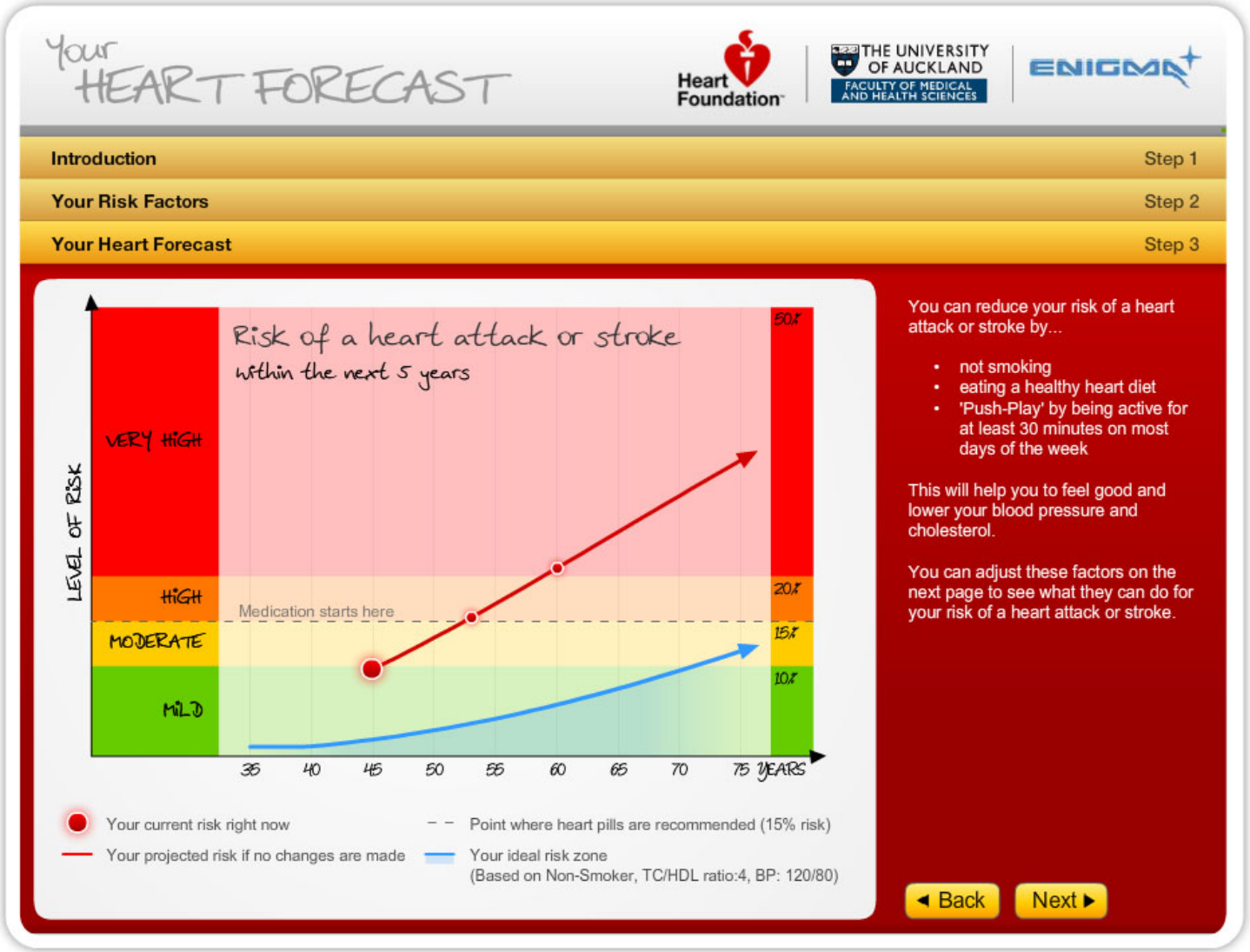
- Conditions of long duration
  - Increasingly account for burden of disease and healthcare cost (because we're good at keeping people alive!)
  - Notably: Cardiovascular disease (CVD), cancer, respiratory diseases (asthma, COPD), musculo-skeletal disorders (arthritis), chronic kidney disease, mental health problems and dementia
- Give patients time to be consumers
- Often engage the system at many points over a long time
  - Challenging ability to coordinate care delivery

What do we (consumers) want from healthcare?

- Life expectancy, QALYs
- Safety (low adverse events and iatrogenic harms), correct and timely diagnosis
- Cost-effectiveness, evidence-based treatment, personalized medicine
- Equity
- To be listened to, our priorities (physio, DNR)



Belts & braces = the traditional system + consumer / activated patient



Innovation Case: Cardiovascular Risk Management

- Decision support interoperates with GP EMR systems ('PREDICT')
- Secondary version used in all cardiac wards
- Consumer tool on Web (Your Heart Forecast)
- Collected data linked for public health research

What's behind the prediction?

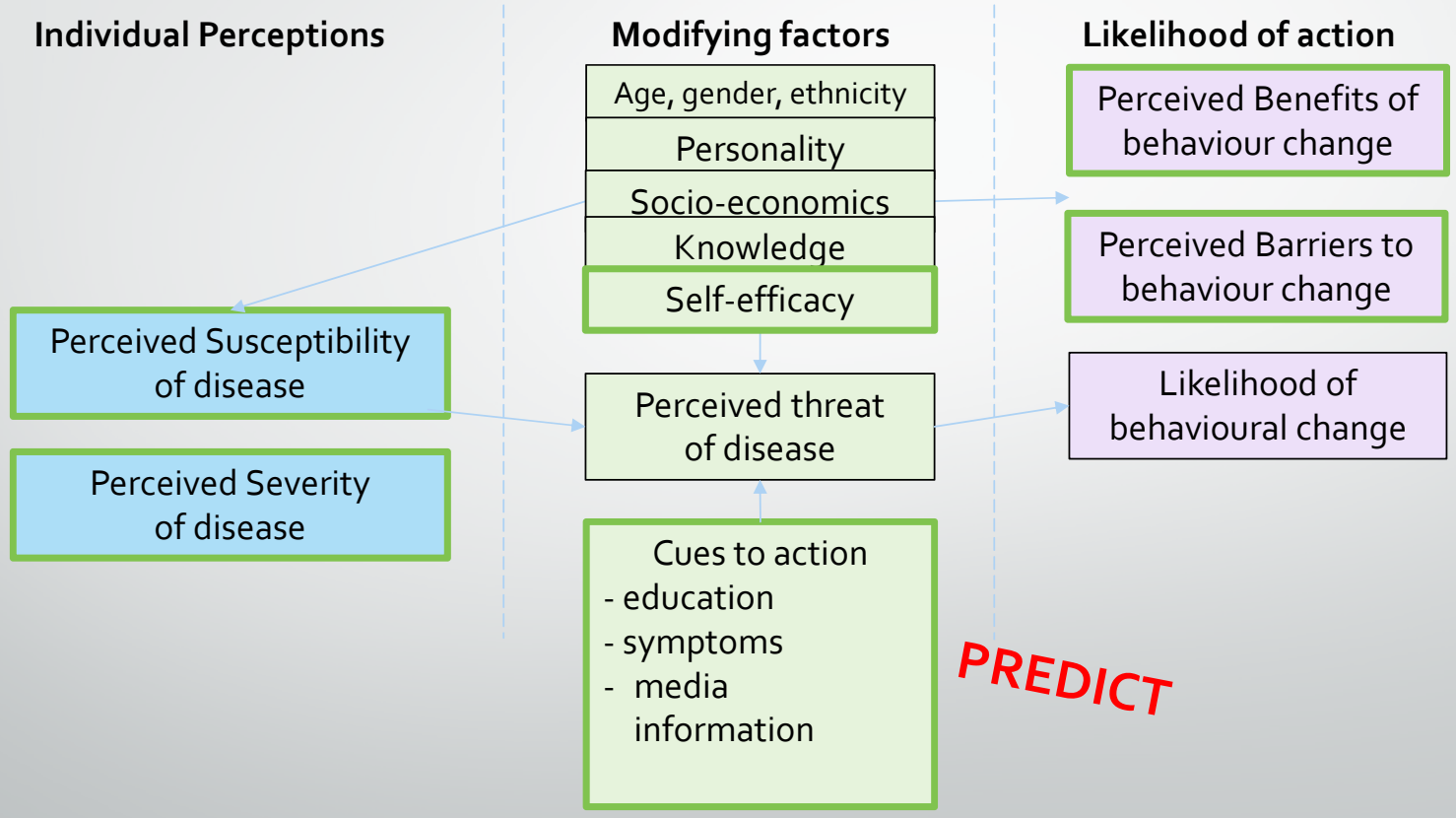
- Regression

$$\operatorname{logit}(\mathbb{E}[Y_i \mid x_{1,i}, \ldots, x_{m,i}]) = \operatorname{logit}(p_i) = \ln\left(\frac{p_i}{1-p_i}\right) = \beta_0 + \beta_1 x_{1,i} + \cdots + \beta_m x_{m,i}$$

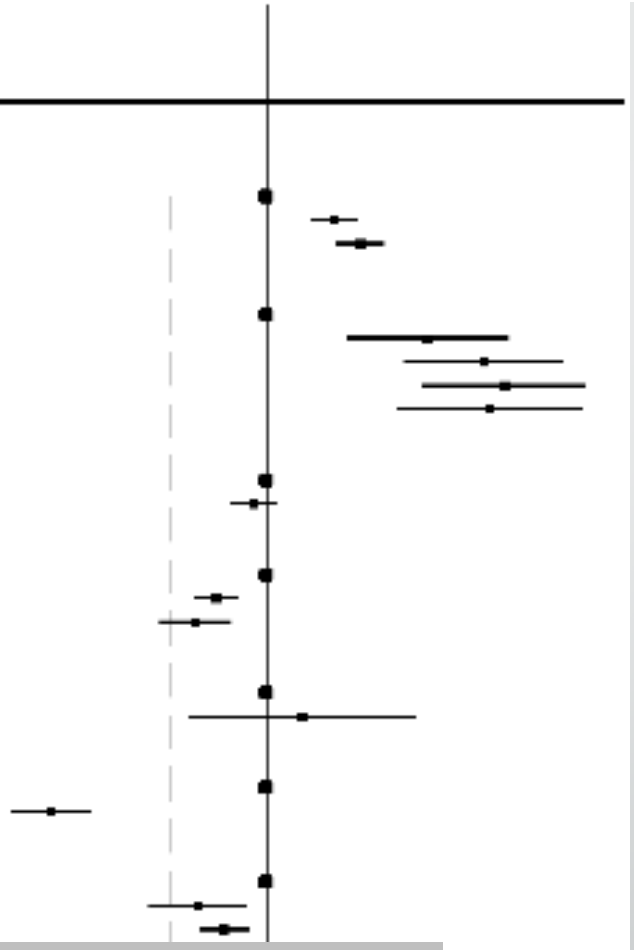
  - Weights are learned by fitting to population health data
- For the scientific mind, seeing the 95% confidence interval of a Beta may be the way to go, but most people will appreciate the graphics
- Most recent results (with Cox proportional hazard model) re-calibrate and emphasize deprivation and ethnicity

Pylypchuk R. et al., "Cardiovascular disease risk prediction equations in 400 000 primary care patients in New Zealand: a derivation and validation study," *Lancet* 391(10133), pp. 1897-1907, 2018.

Health Belief Model



Variable	Persons N	Adherent n	(% of N)	Relative Risk RR	(95% CIs)
Total cohort	36,144	28,889	(79.9%)	-	-
Usual provider index					
Low	12,122	9,354	(77.2%)	1.00	(ref)
Middle	12,148	9,825	(80.9%)	1.04	(1.02 - 1.05)
High	11,873	9,710	(81.8%)	1.05	(1.04 - 1.06)
Age					
45-54 years	1,150	755	(65.7%)	1.00	(ref)
55-64 years	6,086	4,632	(76.1%)	1.09	(1.04 - 1.14)
65-74 years	15,996	12,929	(80.8%)	1.12	(1.08 - 1.17)
75-84 years	11,362	9,341	(82.2%)	1.14	(1.09 - 1.19)
85+ years	1,548	1,231	(79.5%)	1.13	(1.07 - 1.18)
Gender					
Males	17,596	14,222	(80.9%)	1.00	(ref)
Females	18,558	14,667	(79.0%)	0.99	(0.98 - 1.01)
Highest education qualification					
Did not complete high school	17,612	14,374	(80.7%)	1.00	(ref)
High school or equivalent	13,655	10,868	(79.4%)	0.97	(0.96 - 0.98)
University or higher	3,664	2,866	(78.2%)	0.96	(0.94 - 0.98)
Aboriginal status					
Non-Aboriginal	34,925	27,929	(80.0%)	1.00	(ref)
Aboriginal	271	213	(78.6%)	1.02	(0.96 - 1.08)
Language spoken at home					
English only	32,353	26,227	(81.1%)	1.00	(ref)
Language other than English	3,791	2,662	(70.2%)	0.89	(0.87 - 0.91)
Partnership status					
Married or partnered	24,979	20,179	(80.8%)	1.00	(ref)
Single	1,804	1,372	(76.1%)	0.96	(0.94 - 0.99)
Widowed or separated	9,112	7,143	(78.4%)	0.98	(0.96 - 0.99)



Warren, J., Falster, M., Fox, D. & Jorm, L., "Factors Influencing Adherence to Long-Term Use of Statins," Pharmacoepidemiology & Drug Safety, Vol. 22, No. 12, pp. 1298-1307, 2013.

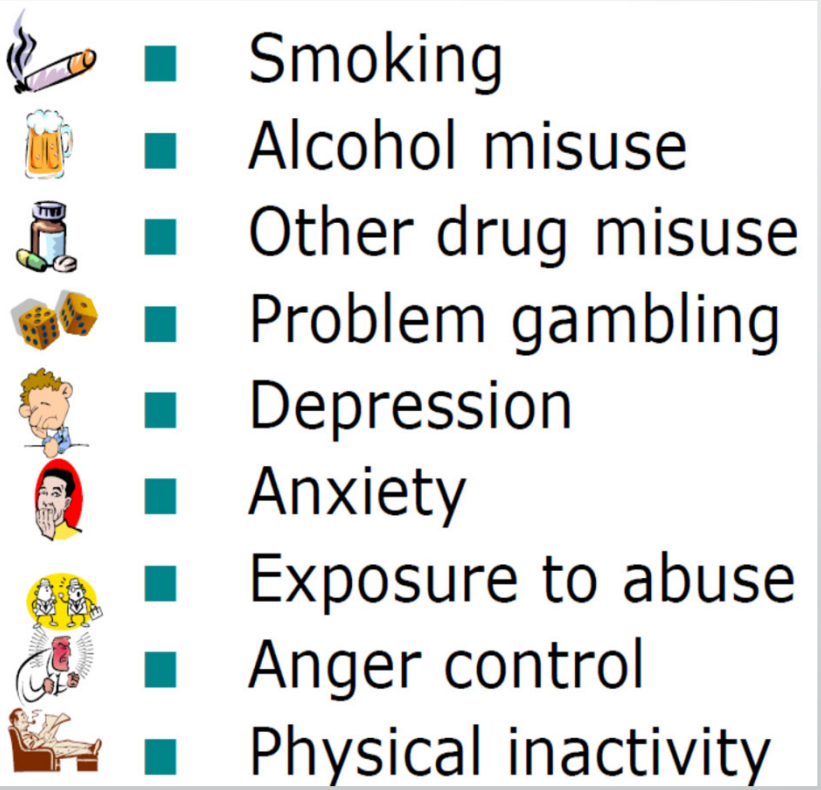
Warren, J., Falster, M., Tran, B. & Jorm, L., "Influence of Continuity of Primary Care on Statin Adherence, " PLoS ONE, Vol. 10, No. 10, e0140008, 2015.

Implications of what we've seen so far

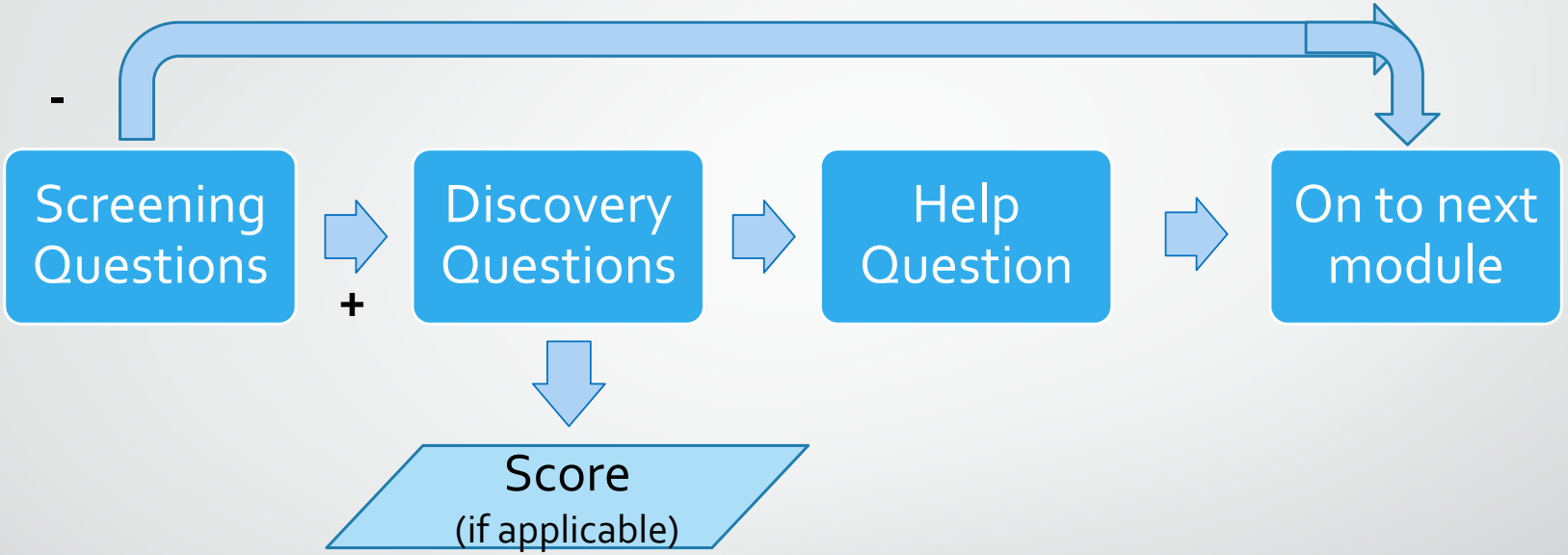
- Clinical decision support tools, beyond promoting evidence based behaviour from clinicians (i.e. traditional Health Informatics – AI in Medicine), also potentially help in achieving an 'activated patient' (a la E.H. Wagner's Chronic Care Model)
- With minor changes in presentation, such tools can be put directly into the hands of the public, encouraging them to seek out a doctor or to help them re-affirm the messages they're getting from 'the system'
- But we can go further…

Innovation Case: Lifestyle and mental health screening

- The electronic Case-finding and Help Assessment Tool (eCHAT)
  - Patient operated screening for a range of common issues
  - Problems assessed with standard instruments where applicable (e.g. PHQ-9)
- Primary use for GP waiting room
  - Summary and detail report forwarded to GP like a lab test result



eCHAT module structure



- Gatekeeps for fast screening where issues are absent
- Asks more depth questions where gatekeeper question(s) positive
  - Scores if standard instrument
- Asks if help is wanted (now or not-right-now) to improve specificity and promote user control

PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✔" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

PHQ-2 screens

eCHAT acceptability, theory

- Initial field trial in general practice
  - iPad provided in reception
  - Acceptable to wide range of ages and ethnicities
  - Translated for Te Reo Māori, Korean
- Integration with stepped care decision support
  - Advice, prescribing, referral
- 'Help question' let's patient choose priority
  - Based on theory of problems occurring in clusters
  - Reduce false-positives

eCHAT acceptability, applications

- Further developed for youth: YouthCHAT
  - Added sexual health questions, adjusted alcohol questions
  - Field trialed for comparison to national face-to-face assessment in low decile schools
- Additional audiences
  - Maternity, veterans (adds PTSD), sports (NZ Rugby)
- Different workflows
  - Email invite for online completion (e.g. from veterans administration worker)
  - Portal based resource

Goodyear-Smith, F., Warren, J., Bojic, M. & Chong, A., "eCHAT: lifestyle and mental health screening," *Annals of Family Medicine*, Sep-Oct 2013, Vol. 11, No. 5, pp. 460-466.

Goodyear-Smith, F., Martel, R., Darragh, M., Warren, J., Thabrew, H. and Clark, T. C. Screening for risky behaviour and mental health in young people: the YouthCHAT programme. *Public Health Rev*, 38 2017.

Lifestyle and mental health screening implications

- e-Screening allows the system to collect information that the consumer can provide
  - Identifies problems that would be overlooked
  - Find out area(s) where help is wanted now
- Then traditional health system responses (e.g. advice, referral, counselling, prescribing) are used to address the issues
  - But in lifestyle and mental health domain, the consumer can do more…

Innovation Case: Youth e-therapy

- Youth mental health initiative as part of an NZ 'national science challenge' for young people

National SCIENCE Challenges

A BETTER START

E Tipu e Rea

SPARX – gamified self-help

- Youth self-help for depression and anxiety as a first-person adventure videogame

Applies well-established methods of Cognitive Behaviour Therapy (CBT), making them more interesting with gamification

E.g. non-player characters and a companion bird called Hope; mini-games, exploration

SPARX: evidence and implementation

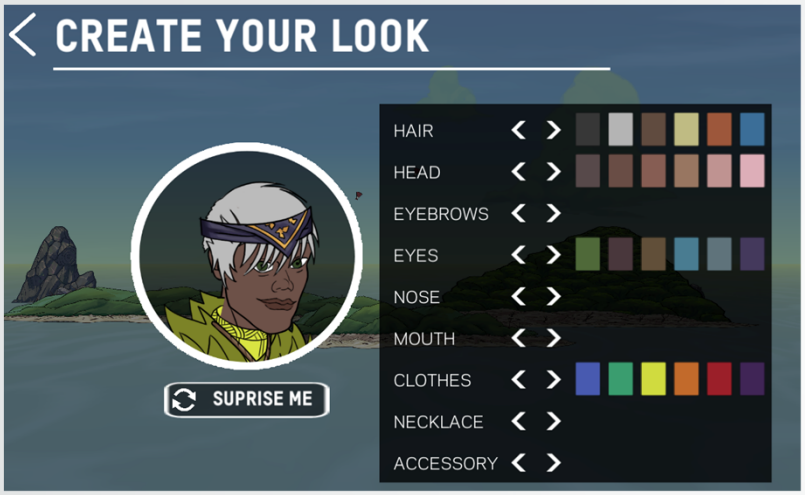
- Not worse than usual care* (face-to-face counselling)
- Available for public use in New Zealand (https://www.sparx.org.nz/)
- Now available reformatted as a mobile app

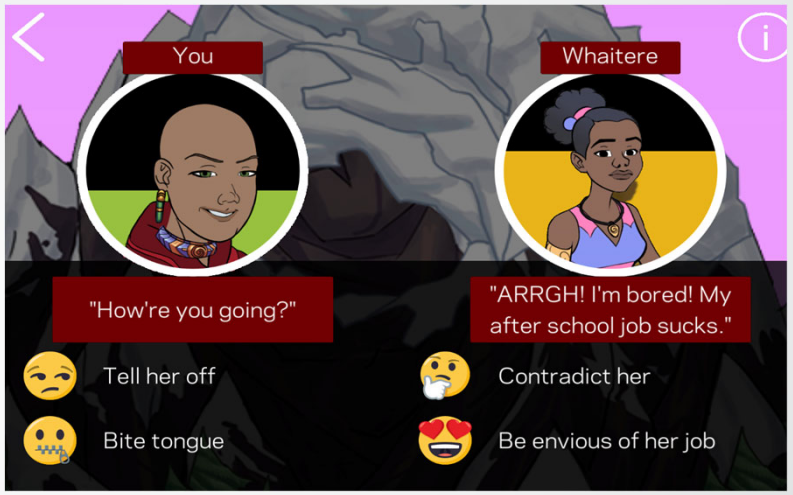
* SN Merry, K Stasiak, M Shepherd, C Frampton, T Fleming, MFG Lucassen. The effectiveness of SPARX, a computerised self help intervention for adolescents seeking help for depression: randomised controlled non-inferiority trial. Bmj 344, e2598, 2012.

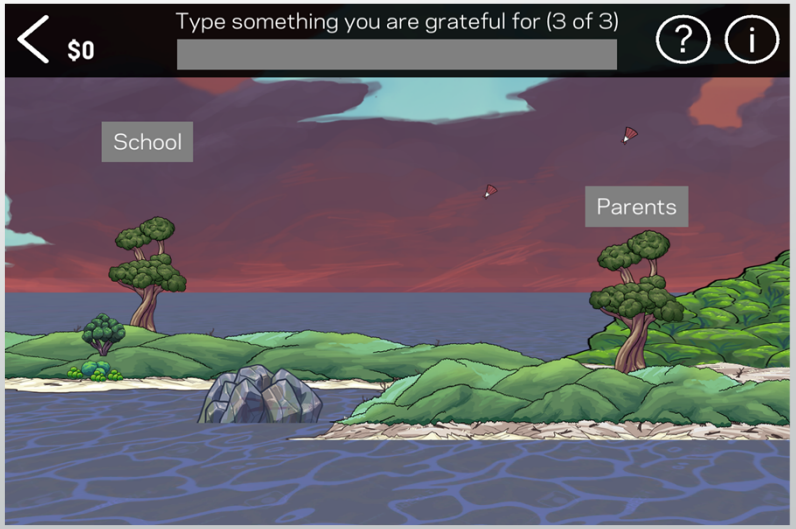
HABITs – health advances through behavioural intervention technologies

- A project of 'A Better Start' building on SPARX tradition of gamified CBT
  - Mobile friendly, 'bite size' with more user selection
- Linked to screening (YouthCHAT) for low decile secondary schools
  - Provide summary feedback to school staff
  - Tailor messages to youth based on screening
- Focus on acceptability to Māori and Pacific youth
  - Co-design and stakeholder engagement

The Quest – *Te Whitianga*

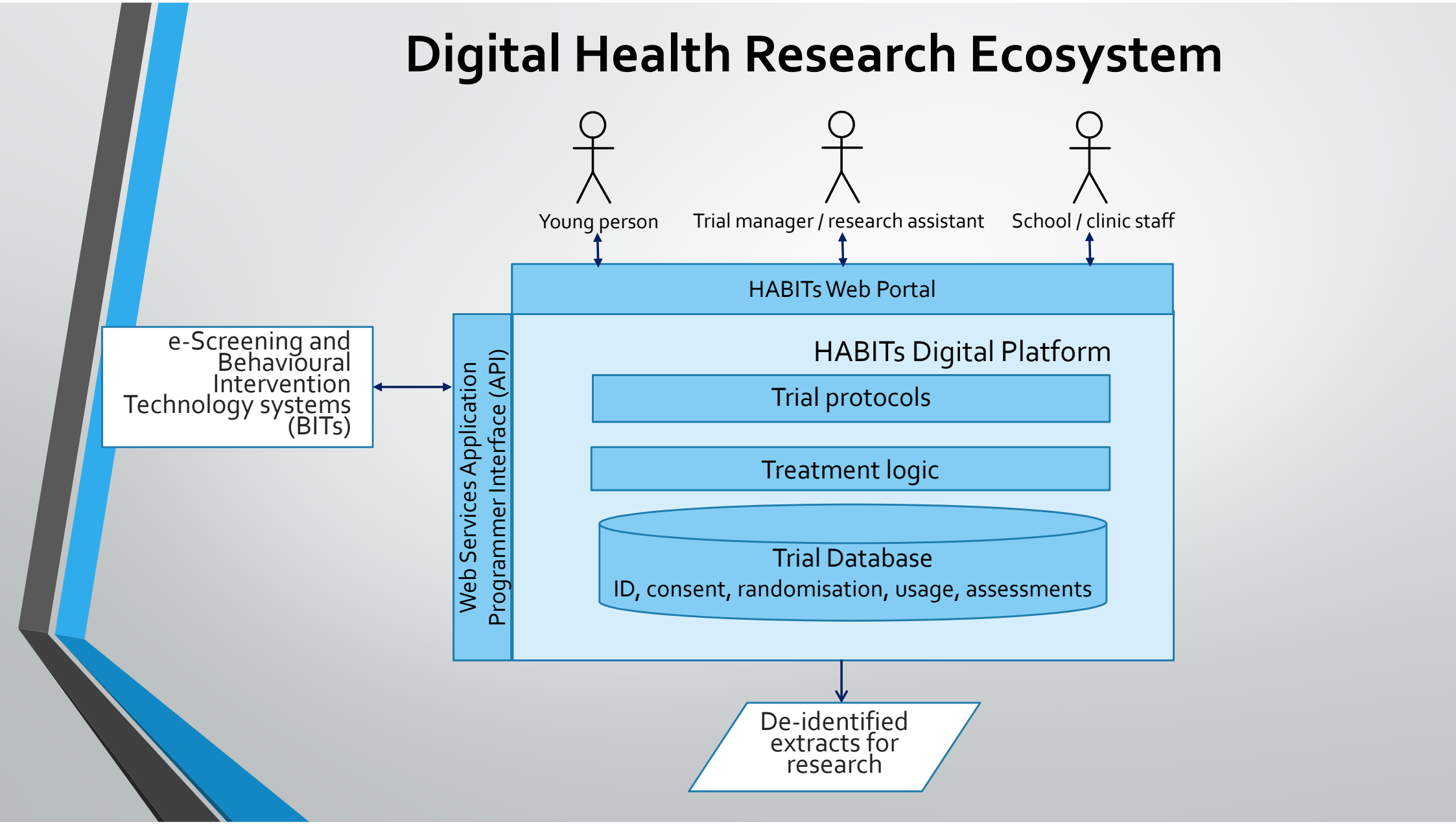






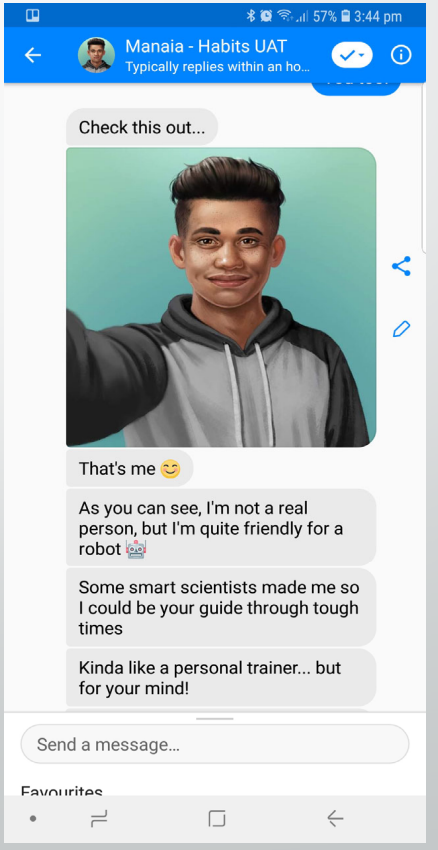
Remind, Relax, Reengerise, Rethink, Resolve, Relate

Digital Health Research Ecosystem



An ‘ecosystem’ for youth mental health

- The goal is to use the HABITs platform API to allow more intervention technologies to join in
- Different combinations and variants for different trials and contexts of use
- Have also created a mental health chatbot agent (delivered via Facebook Messenger) as the central interaction technique
- Planning to integrate mobile SPARX and others



Youth e-therapy implications

- The consumer (young person, in this case) can directly take action to manage their issues with the support of e-therapy applications (e.g based on CBT and positive psychology)
  - Potential for clinician monitoring of adherence/persistence with treatment
- Links naturally with e-screening
  - Note issues, track progress, advise if in the 'sweet spot' for self-management

Not an isolated case

- IT in the hands of consumers effective for other health behaviours (things the consumer can change for themselves)
  - Smoking cessation
    - Whittaker R, McRobbie H, Bullen C, Rodgers A, Gu Y. Mobile phone-based interventions for smoking cessation. *Cochrane Database Syst Rev*. 2016 Apr 10;4.

      (evidence mainly for SMS message interventions)
  - Probably exercise and rehabilitation

www.abc.net.au

Conclusion

- Potential for a ‘belts and braces’ relationship between the traditional healthcare system and the empowered health consumer in IT-enhanced chronic condition management
- Technology lets ‘the system’ perceive problems that were hidden
  - Inequity, gaps in individual adherence, problems not known until asked about
- Technology lets consumers do things for themselves
  - Become motivated, self-assess, provide information they know, ask for help
  - For mental health: help themselves with mild to moderate problems, or as an adjunct to traditional therapy

Thank you

Prof Jim Warren, jim@cs.auckland.ac.nz,
http://www.cs.auckland.ac.nz/~jim/