



Disability and Social Inclusion Seminar 15th July 2014

Professor Amanda Burls
Director of ThinkWell
City University London

www.iThinkWell.org



AIM

“To improve the health and wellbeing of citizens across the world by enabling them to make informed decisions about lifestyle, diet and health interventions through public-led health discussions, education and research, using the internet and the mass media as the fundamental tools”

September 29, 2014



The birth of ThinkWell

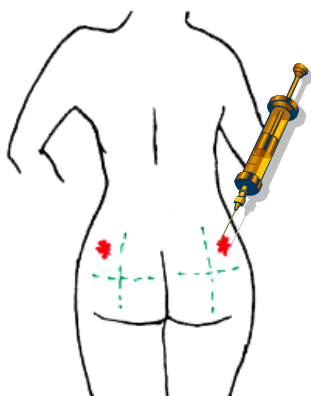
Profes-
sional
life



Personal
life

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Rheumatoid arthritis



Personal
life

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The gold clinic...



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What've you tried for your RA?



8 Foods That Fight Arthritis

Written by Denine Stracker, RN

Medically Reviewed on May 1, 2013 by [George Krucik, MD, MBA](#)



6 of 11

Ginger

Ginger has been used for [thousands of years](#) to treat colds, nausea, migraines, and hypertension. Although [clinical studies report mixed results](#) regarding ginger's role in arthritis, the [Journal of Medicinal Food](#) gives evidence to support the anti-inflammatory and antioxidant role of ginger.

To add more ginger to your diet, try grating fresh ginger over sautéed vegetables, adding sliced ginger to tea, and sprinkling ground ginger in baked good batters.

NOTE: Ginger acts as a blood thinner, which could interact with blood thinning medication. Be sure to check with your physician before adding these foods to your diet.



[Pollywollydoodle](#)

Anyone tried an elimination diet to see if different foods effect their RA?

● 13 replies

I have been taken off methotrexate just now as my liver is suffering and wondered if anyone had tried to eliminate foods which might aggravate their arthritis or had tried a full elimination diet. Looking for an alternative approach while I have no other choice really!!

Tags [Arthritis](#) [LIVER](#) [elimination](#) [RA](#) [Methotrexate](#)

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TildaT

I eliminated wheat and don't touch bread or wheat flour even now 10 months since I begun because avoiding it has helped with my gallstones and digestive system a lot - not sure it makes any difference to joints though.

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Trish53

I feel sure there's some connection, but this has been dismissed by my Rheumy nurse. Like Mads, I've tried to follow elimination diets but I slip up after a day or two, as the suspect items like gluten etc are hidden in so many foods!!

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she said that most GPs are sceptical and my friend who is a GP always looks a bit amused at my food related ideas.



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The public and patients need support and good information

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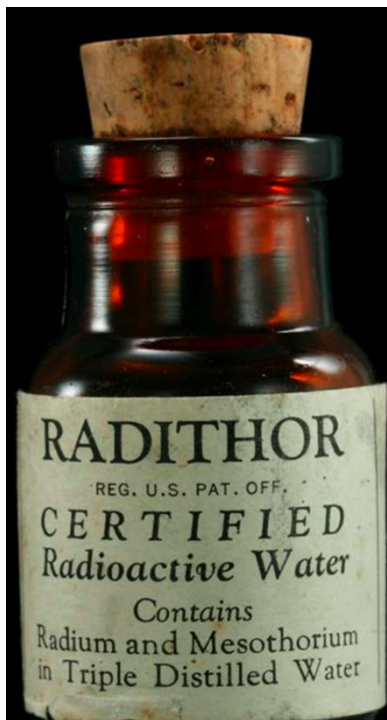
Individual experience is not enough

Liz says:

November 30, 2012 at 3:10 pm

something is good for you and bad for you depending on who you ask. I just try things for myself. My body chemistry is different than yours so what works for me may not work for you.

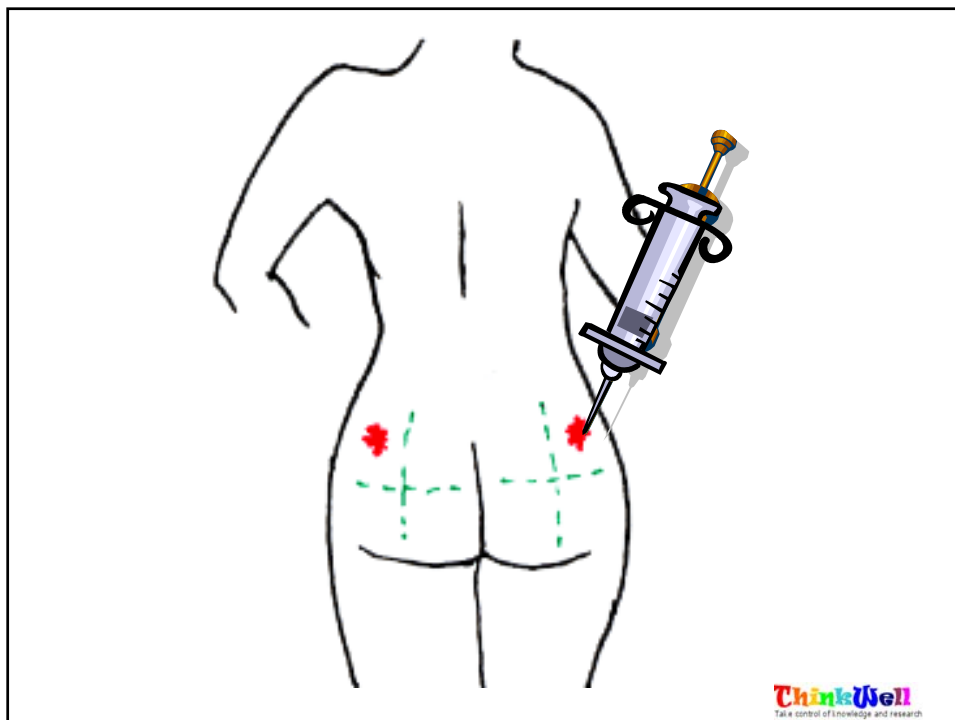
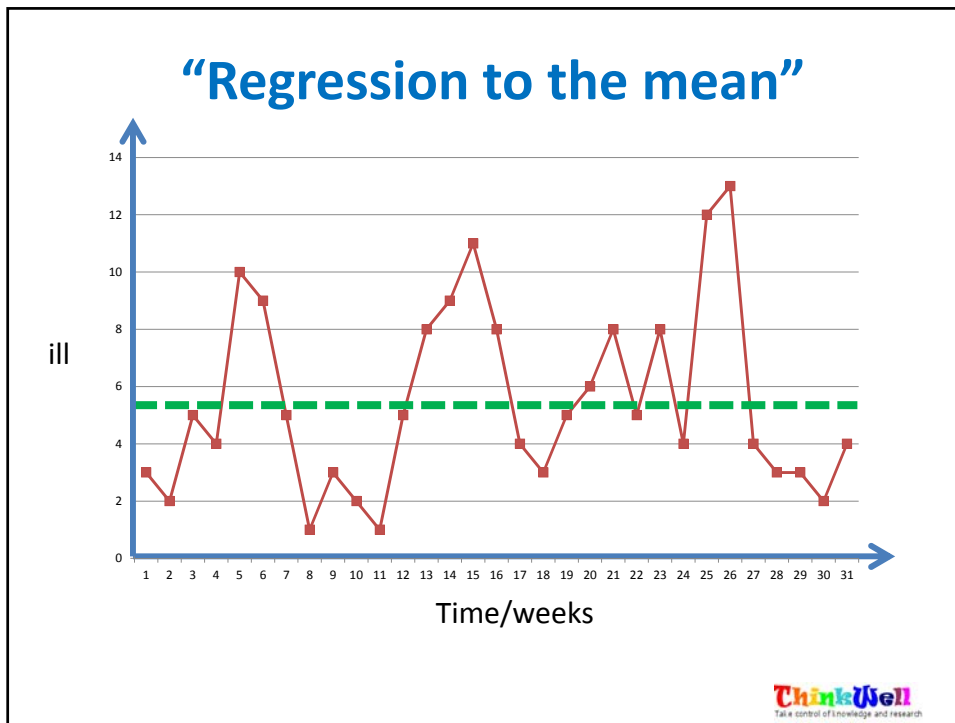
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"The Radium Water Worked Fine Until His Jaw Came Off"

Wall Street Journal (1928)

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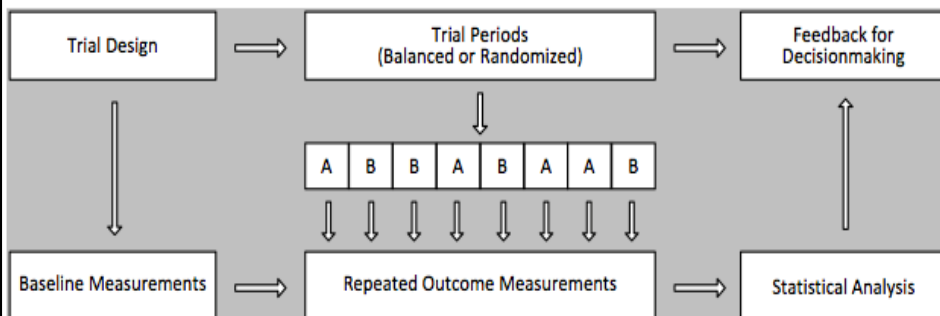


“It could have happened by chance!”



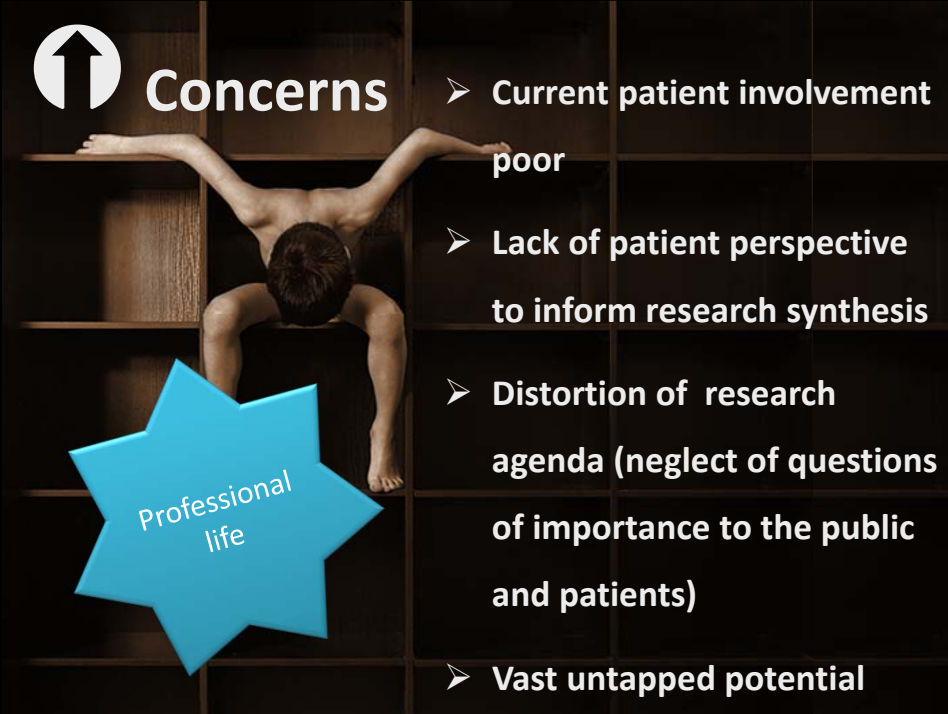
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“N of 1” trials



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 **Concerns**

- Current patient involvement poor
- Lack of patient perspective to inform research synthesis
- Distortion of research agenda (neglect of questions of importance to the public and patients)
- Vast untapped potential

Professional life

Adalimumab
(Anti-TNF drug for arthritis)



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2006 Meeting to consider how to

- Undertake health research to an agenda set by the public.
- Make accessible, scientific evidence on health and well-being
- Help people understand what makes research trustworthy and make sense of evidence
- Identify important gaps in our knowledge
- Involve the public and participants in the design of studies
- Undertake research, in partnership with the public, using the internet and mass media.
- Investigate the methodological issues raised by conducting research using the internet and mass media.
- Explore the ethical implications of internet research

September 29, 2014

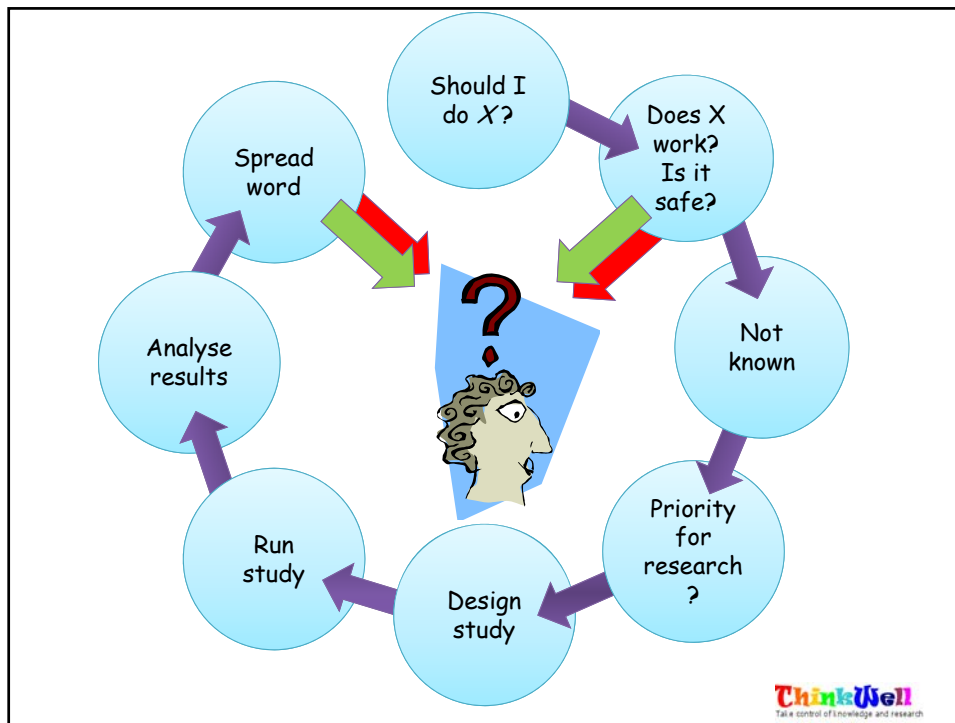


Fundamental concept

To use modern communication technologies to engage citizens in

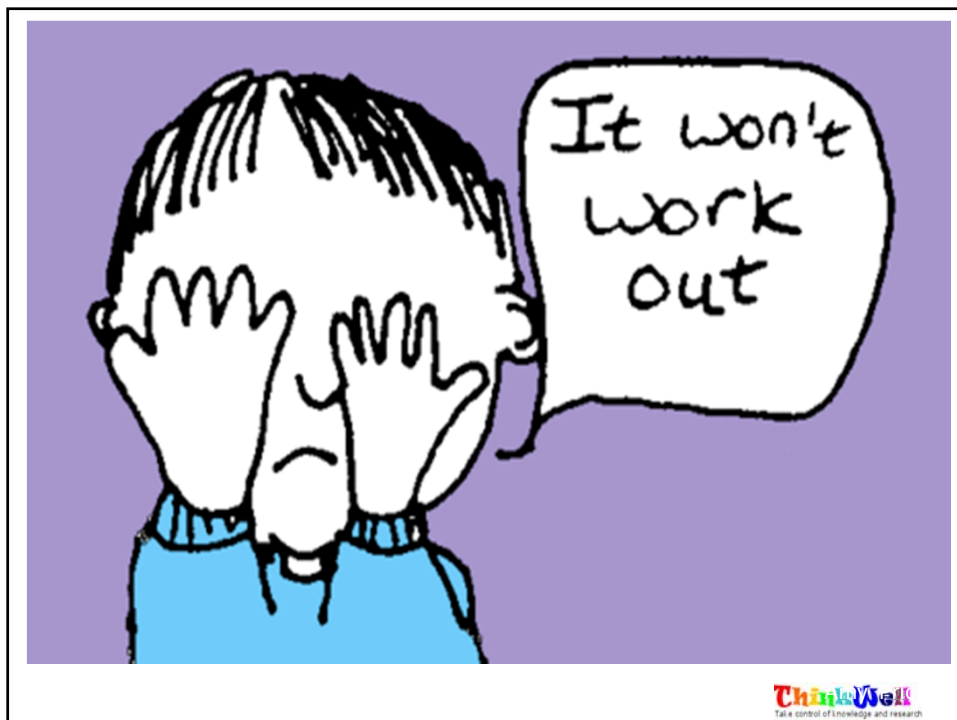
- identifying their own information needs
- prioritising uncertainties that need to be addressed by research
- participating in the design of studies
- participating in online trials of interventions people can do for themselves, where the outcome can be reported or measured by participants themselves
- freely providing and sharing health data via the internet or mobile technologies.

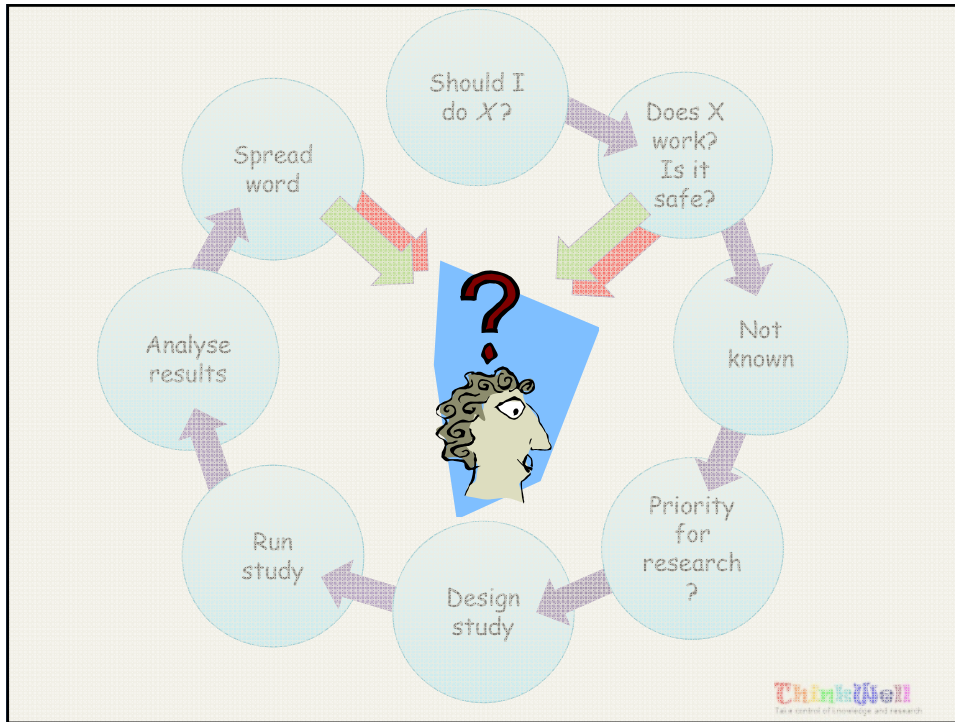




Focus on self-management to improve health or maintain health

- Interventions people can do for themselves, without need for health care professional, such as
 - Diet: exclusion, change pattern, caloric restriction, inclusion
 - OTC medication or device (e.g. light for cold sores)
 - Change sleep or physical activity patterns/behaviours
 - Psychological intervention (e.g. CBT, mindfulness, gratitude diary, writing therapy, brain training)
 - Behaviours (e.g. watch less TV, no work in evenings)
 - Get a pet
 - Weigh daily or weekly
- Health outcome that can be measured or reported by the person themselves, such as
 - Weight/BP/Blood glucose
 - Mood/Anxiety/Stress/Happiness
 - Rash
 - Pain
 - Quality of Life/quality of relationships/quality of sleep





PlantsRule says:

November 4, 2012 at 3:09 pm

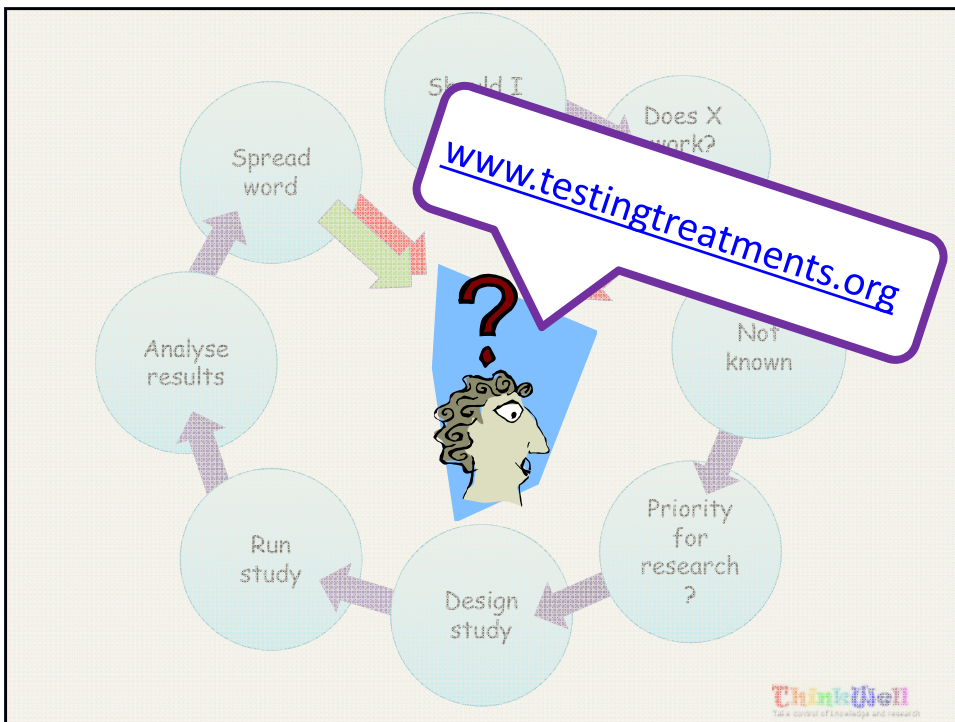
Cate

I also have trouble determining what is healthy and what is not because one day something is healthy and the next it give you cancer.


Evidence to the rescue



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www.testingtreatments.org


Testing Treatments *interactive*
 Promoting better research for better healthcare

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How YOU can promote better research for better healthcare

Start here:

- [Why do we need fair tests of treatments?](#)
- [What are fair tests of treatments?](#)
- [What can be done to improve tests of treatments?](#)
- [How can YOU help to improve tests of treatments?](#)

Caution

This website is NOT about whether particular treatments work or not. For up to date information about SPECIFIC treatments, we recommend:

- [PubMed Health](#) | [TRIP database](#)
- [NHS Choices](#) | [NHS Evidence](#)



[Browse videos, cartoons and more](#)

We are always on the lookout for great interactive resources about fair tests of treatments. [Please tell us if you find any you think we should include.](#)

What's new?

New resources


- [Correlation is not causation. Let's say that correlation is not causation!](#)
- [Routine use of unvalidated therapy is less than careful research to assess the effects of treatments](#)
- [Tamiflu: securing access to medical research](#)

Testing Treatments Twitter

- Brilliant article from BBC News - Do doctors understand test results? <http://t.co/O2o9nw> PM July 07, 2014 from [Twitter for Websites](#)

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117

PlantsRule says:

November 4, 2012 at 3:09 pm

Cate


I also have trouble determining what is healthy and what is not because one day something is healthy and the next it give you cancer.

I myself am not an expert in statistics, but I know that its not as simple as correlating two items together....

This is why I have to side with the scientist who has a lifetime of work to back his claims.

PhysiciansCommittee for Responsible Medicine 

Foods and Arthritis

Millions of people suffer from painful and swollen joints associated with arthritis. In the past, many doctors told arthritis patients that dietary changes would not help them. However, this conclusion was based on older research with diets that included dairy products, oil, poultry, or meat.^{1,2} New research shows that foods may be a more frequent contributor to arthritis than is commonly recognized. It is clear that, at least for some people, a healthier menu is the answer.



<http://www.pcrm.org/health/health-topics/foods-and-arthritis> accessed 14/07/14

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A systematic review of randomized controlled trials comparing any dietary manipulation with an ordinary diet found:

- 8 trials, with a total of 366 patients
- 1 trial of fasting, followed by 13 months vegetarian diet found that it might reduce pain (mean difference on a 0 to 10 scale -1.89, 95% CI -3.62 to -0.16)
- 1 trial found that a 12-week Cretan Mediterranean diet might reduce pain (mean difference on a 0 to 100 scale -14.00, 95% CI -23.6 to -4.37)
- The effects of vegan eating plans and elimination diets are uncertain.
- When comparing any dietary manipulation with an ordinary diet they found the intervention arm to have
 - a higher total drop-out of 8% (RD 0.08, 95% CI -0.01 to 0.17)
 - higher treatment-related drop-out of 5% (RD 0.05, 95% CI -0.03 to 0.14)
 - higher weight loss (WMD -3.24, 95% CI -4.81 to -1.67 kg) in the diet groups

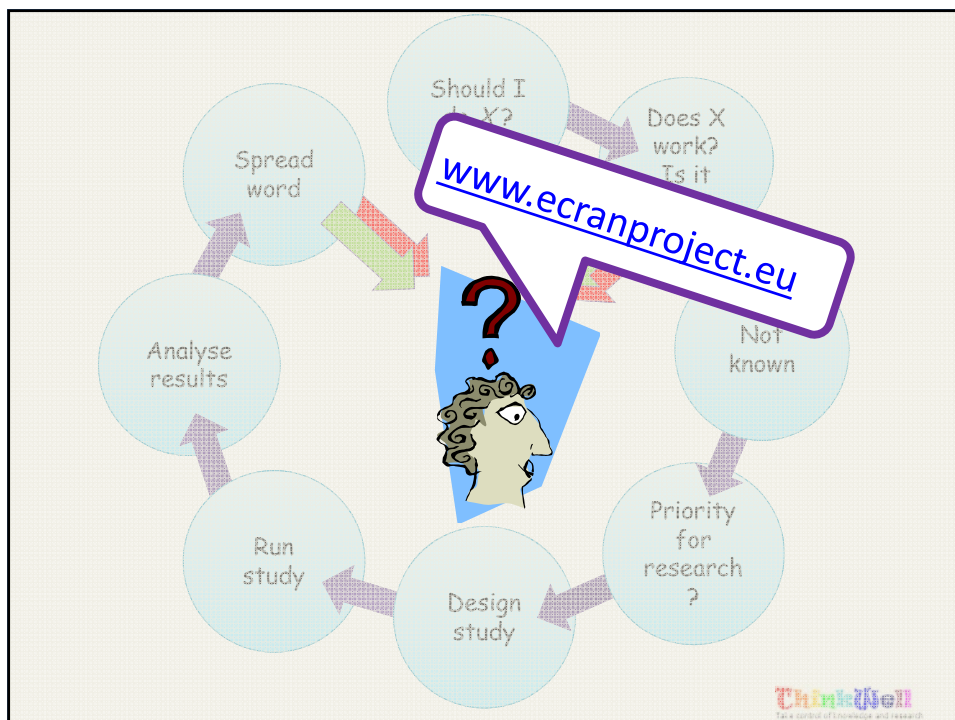
Smedslund G1, Byfuglien MG, Olsen SU, Hagen KB. Effectiveness and safety of dietary interventions for rheumatoid arthritis: a systematic review of randomized controlled trials. J Am Diet Assoc. 2010 May;110(5):727-35. doi: 10.1016/j.jada.2010.02.010.

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Cochrane Review plain language summary:

“It is uncertain whether diets improve pain, stiffness and the ability to move better.”

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How can we tell if a treatment works?

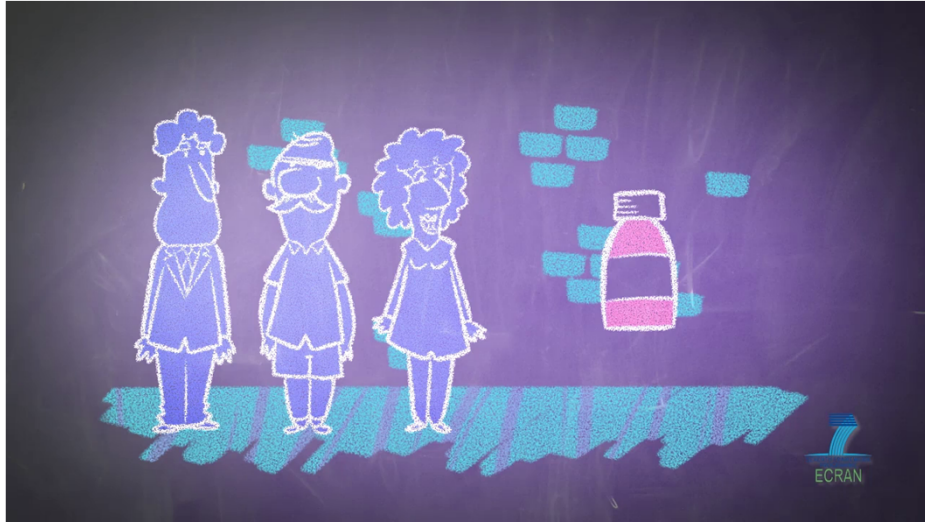
CLINICAL RESEARCH MATTERS TO YOU:
DO YOU WANT TO KNOW MORE?



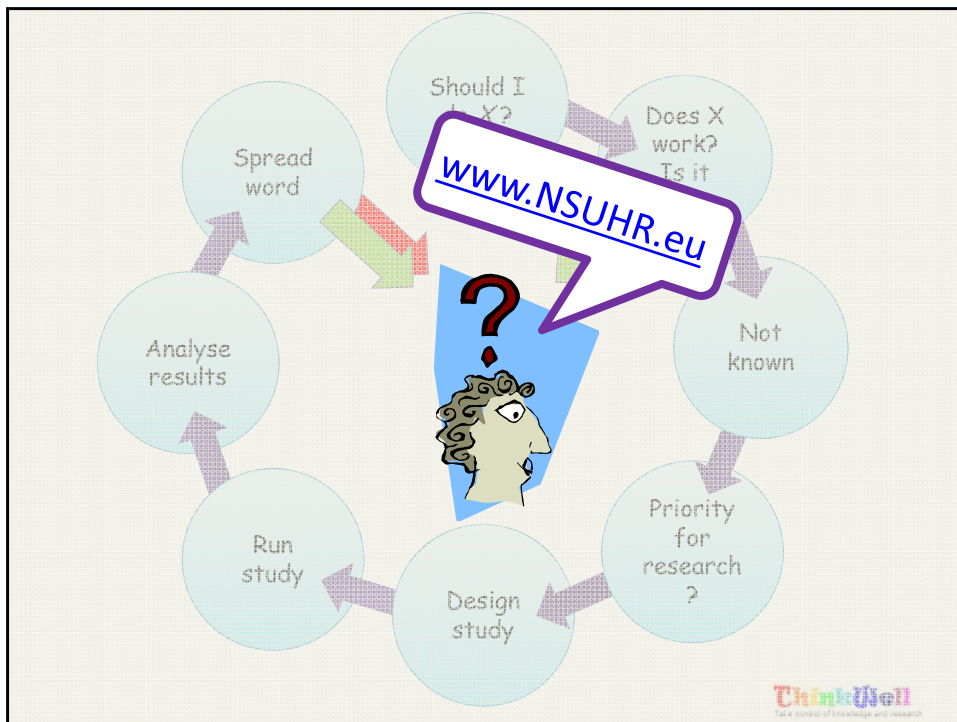
Blinding



Randomisation



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www.NSUHR.net



An international Network to Support Understanding of Health Research

Welcome Evaluation Resources About us Members Submit a Resource FAQs

Understanding health research

Exaggerated messages from health research generate both fear and hope out of all proportion to the actual dangers people face, or the benefits that treatments offer in reality.

The goal of the international Network to Support Understanding of Health Research (NSUHR) is to help those who are trying to help people become more discriminating users of health research.

We do this by assembling high quality resources – books, videos, websites, games, etc. – which help people to develop these skills, together with any [evaluations](#) of the effects of these resources.

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The NSUHR website has been created by and for an [international Network](#) of people

Recent Posts

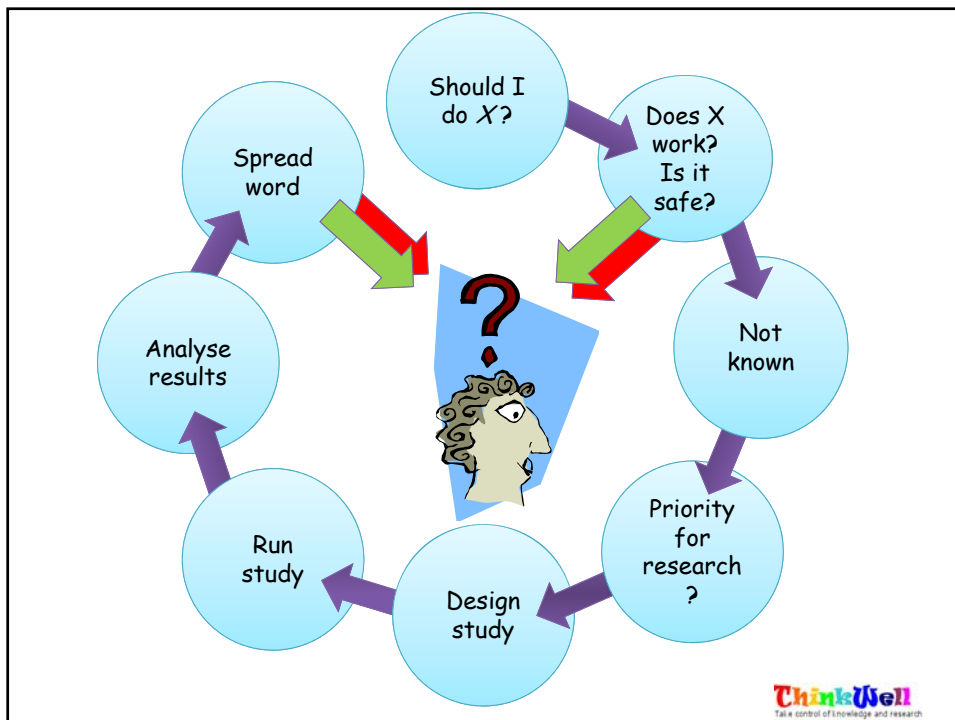
- ePrognosis
- The Knowledgeable Patient
- Clinical trials
- Maths and Our Health
- Patients Participate!

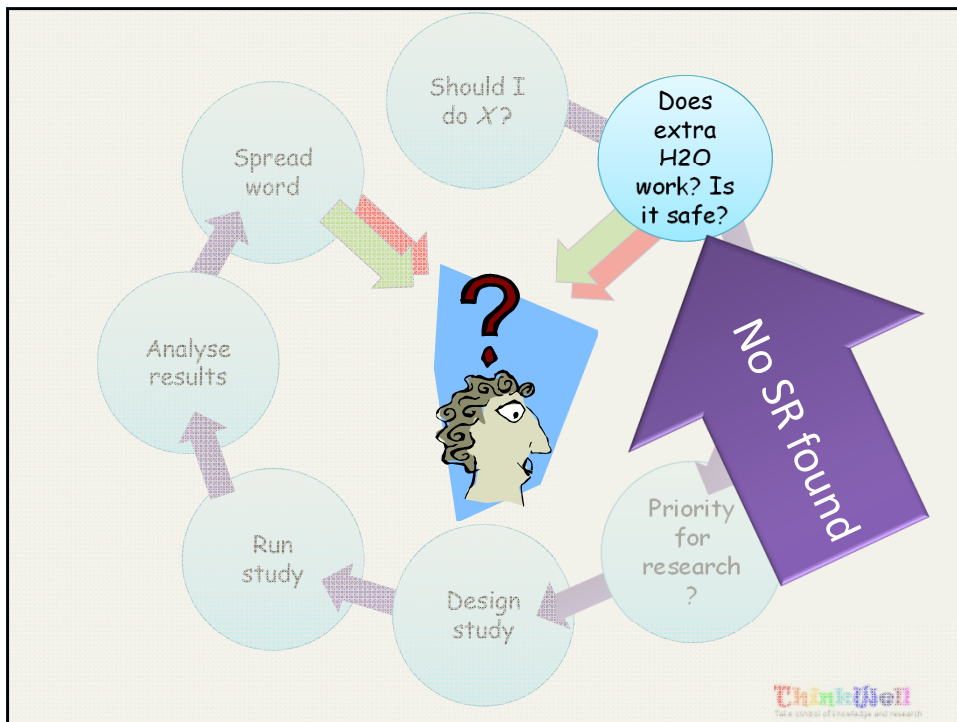
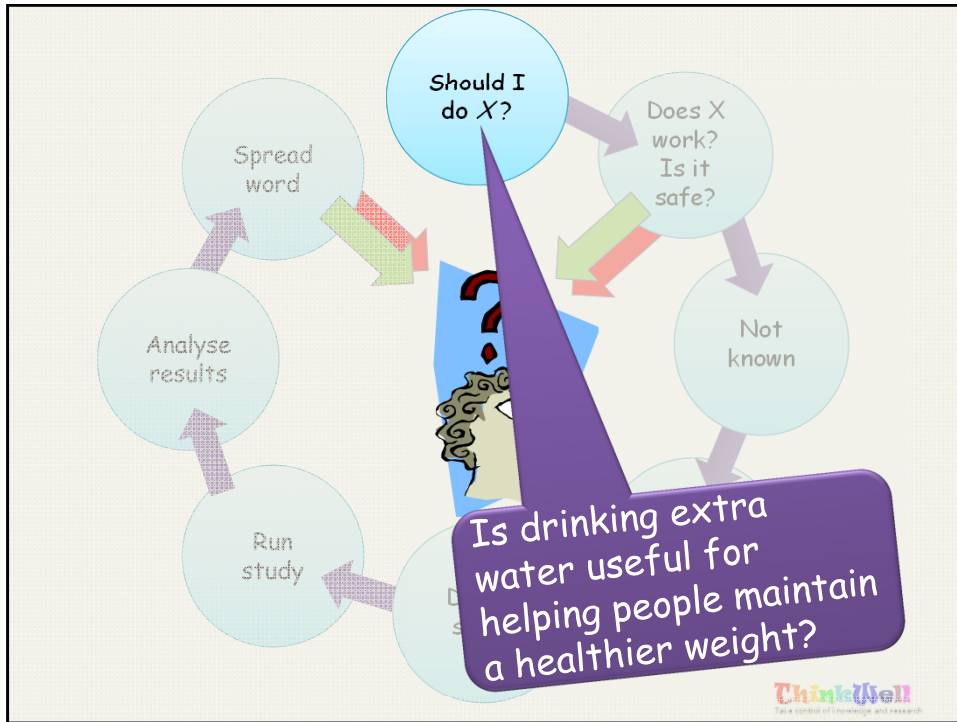
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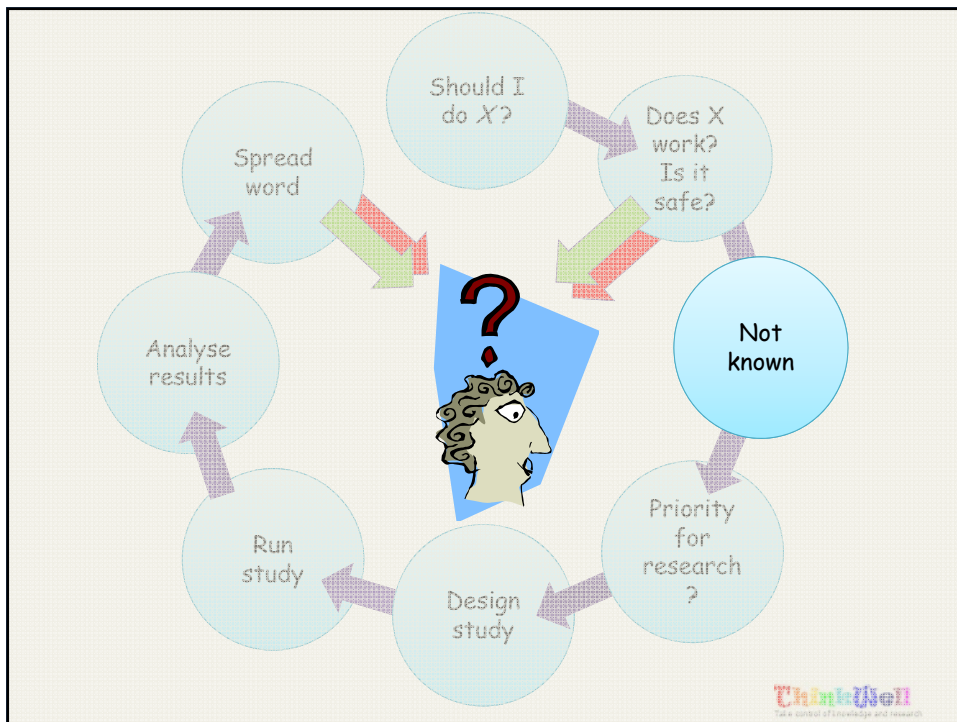
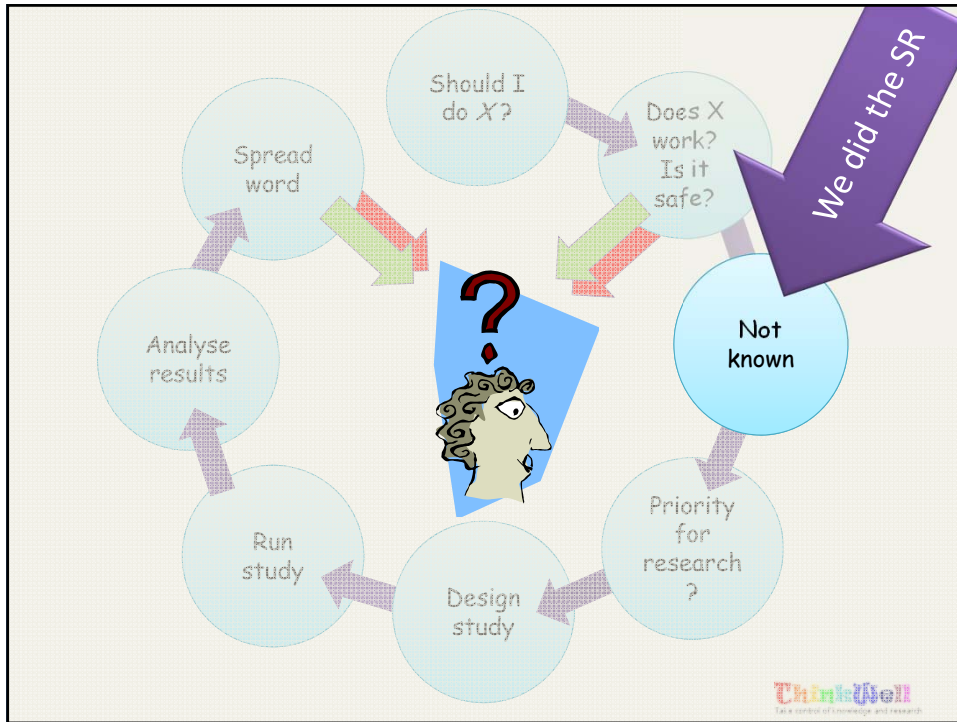
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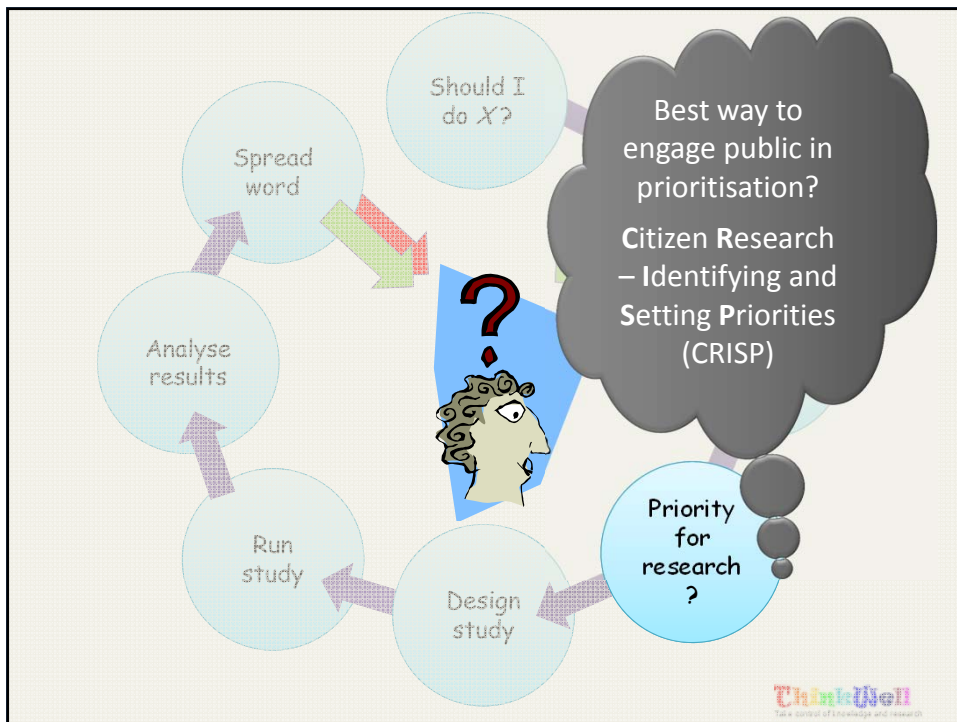
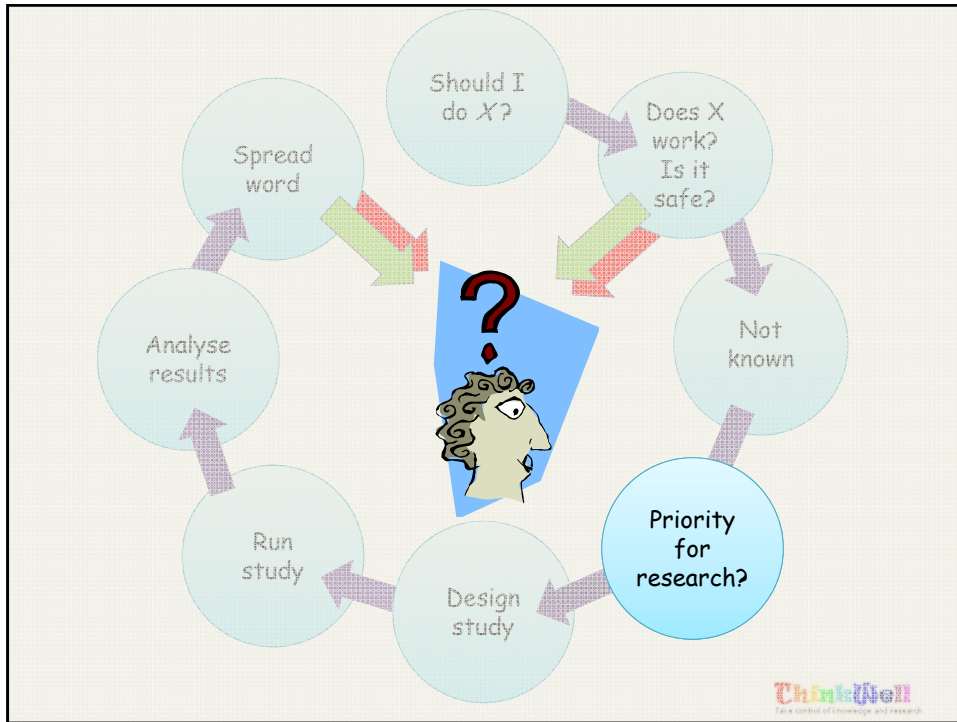


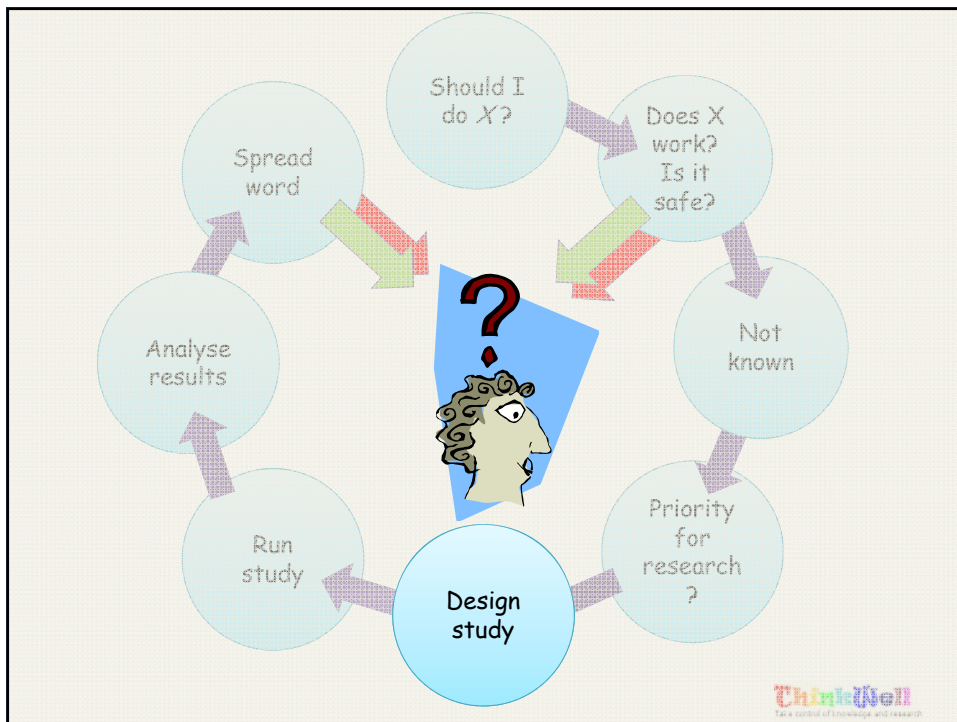
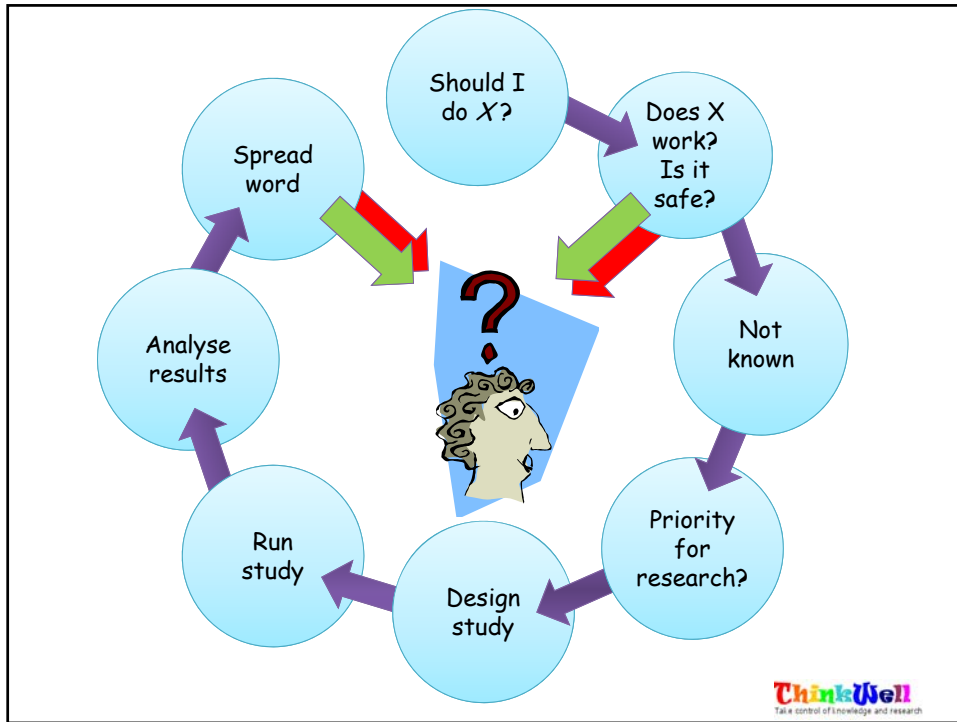
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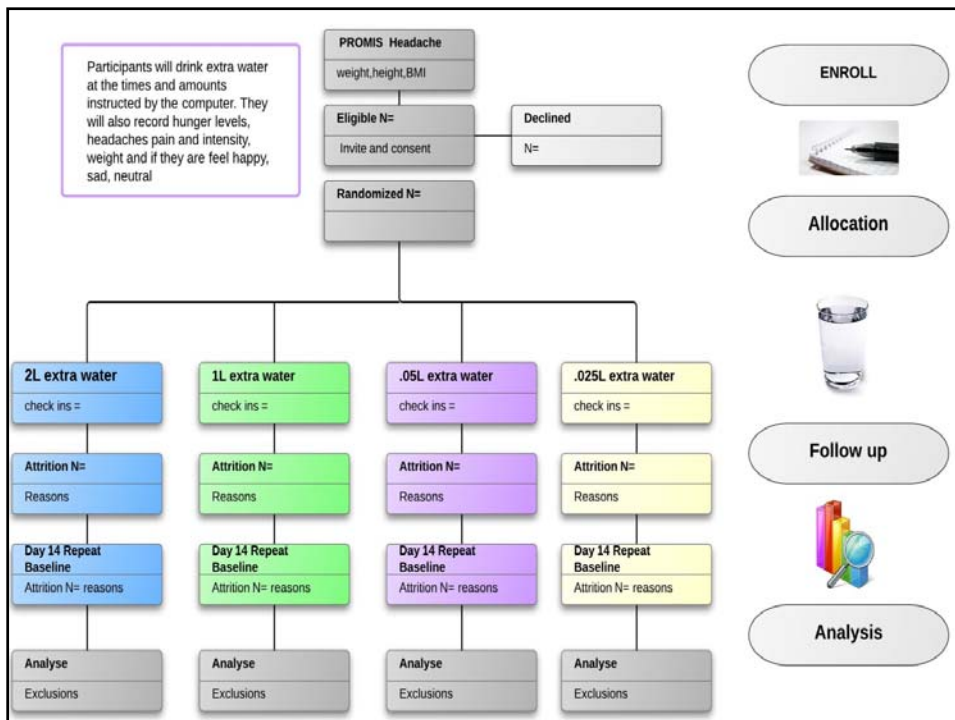
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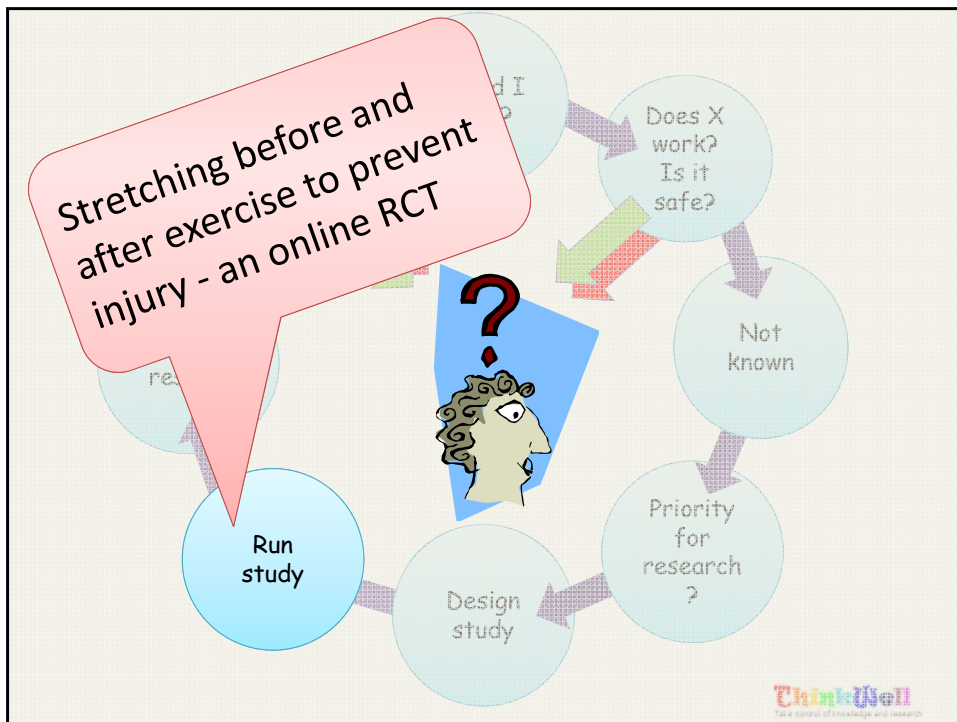
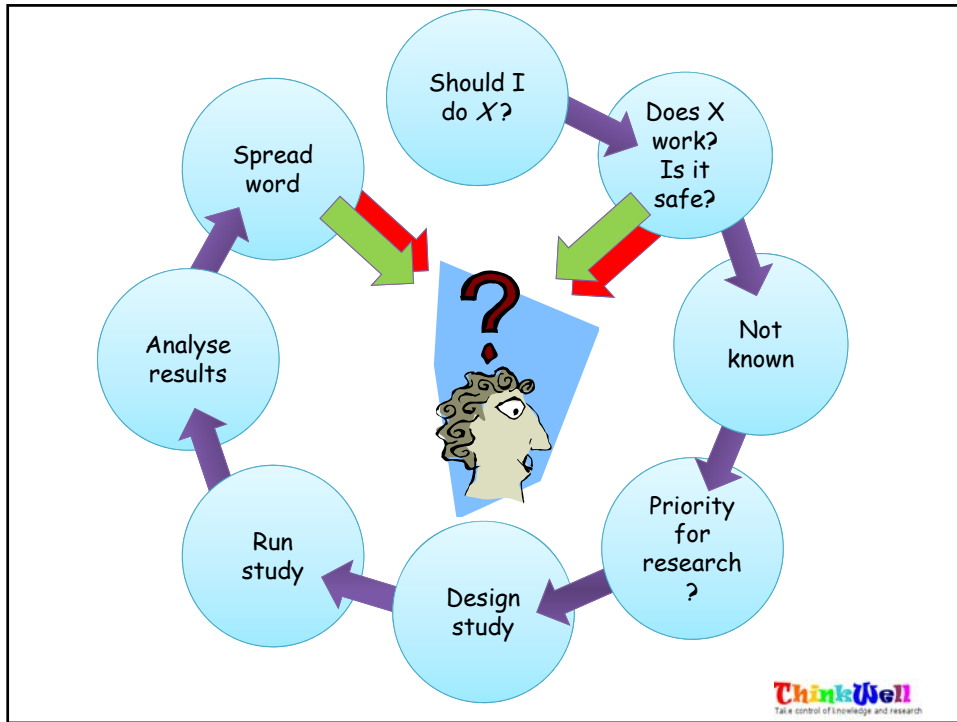


H₂O Study

↓

Does drinking water reduce headaches?





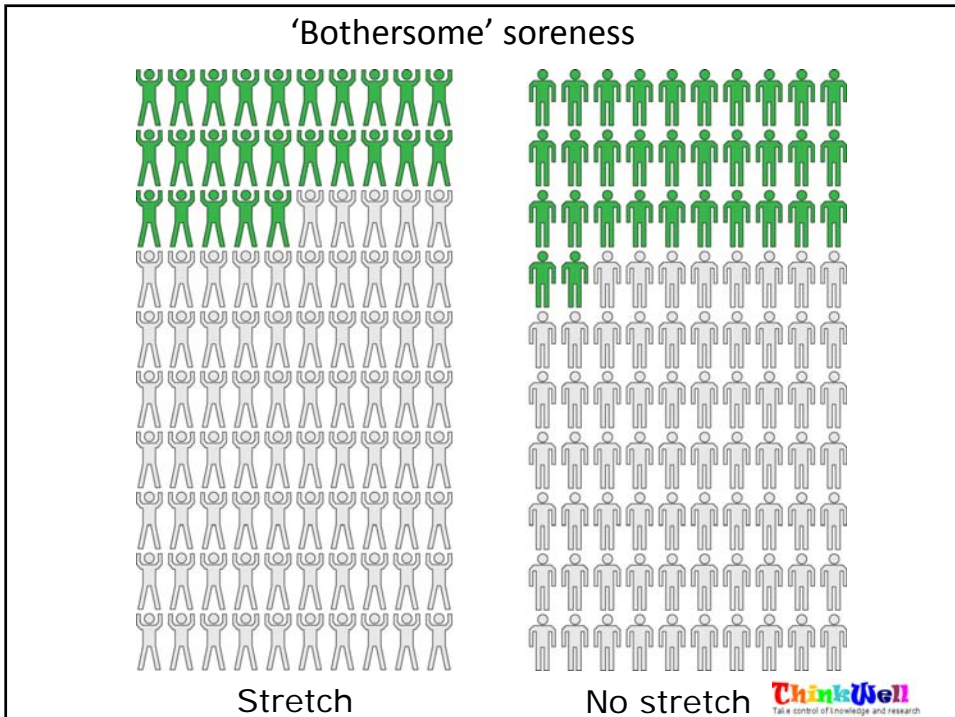
<http://bjsm.bmj.com/cgi/content/abstract/bjsm.2009.062232v1>

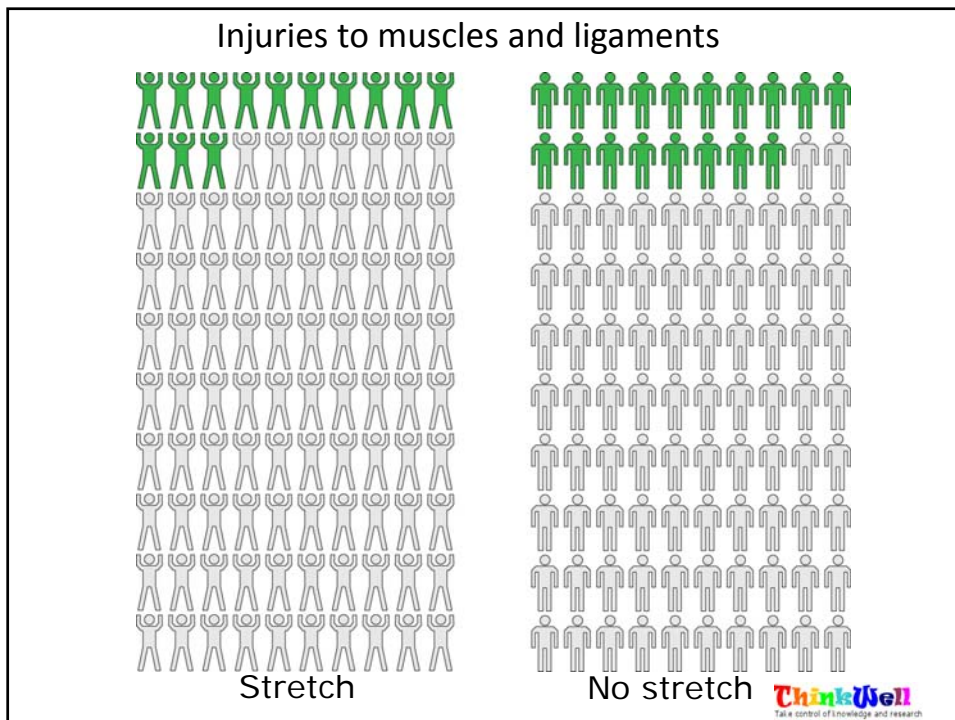
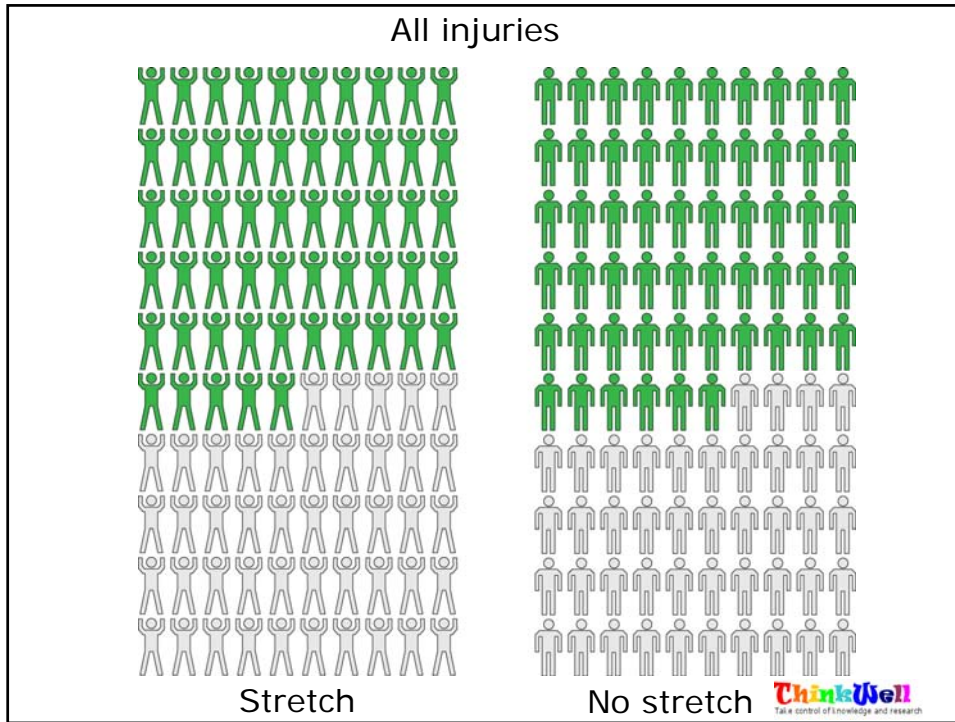


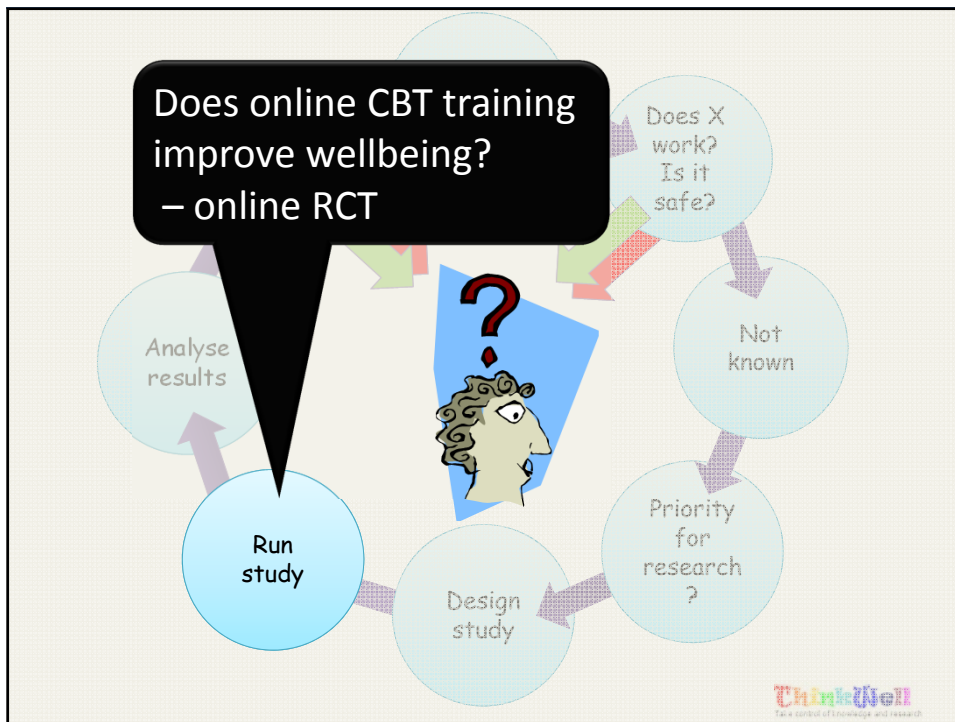
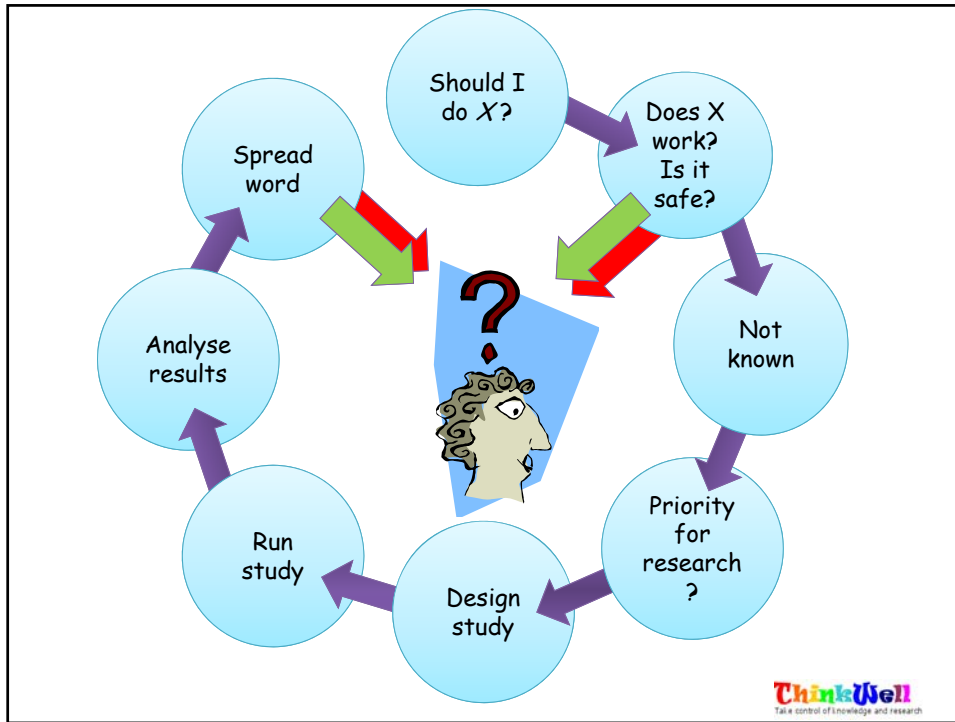
A pragmatic randomised trial of stretching before and after physical activity to prevent injury and soreness

Gro Jamtvedt, Robert D Herbert, Signe Flottorp, Jan Odgaard-Jensen, Kari Håvelsrud, Alexandra Barratt, Erin Mathieu, Amanda Burls and Andrew D Oxman

Br. J. Sports Med. published online 11 Jun 2009;
doi: 10.1136/bjsm.2009.062232







Original Paper

Effectiveness of a Web-Based Cognitive-Behavioral Tool to Improve Mental Well-Being in the General Population: Randomized Controlled Trial

John Powell¹, MBChir, MSc, PhD, FFPH; Thomas Hamborg², PhD; Nigel Stallard², PhD; Amanda Burls¹, MBBS, MSc, FFPH; Jaime McSorley³; Kylie Bennett⁴, BSc, BA(Hons); Kathleen M Griffiths⁴, BSc(Hons), PhD; Helen Christensen⁵, PhD

¹Department of Primary Care Health Sciences, University of Oxford, Oxford, United Kingdom

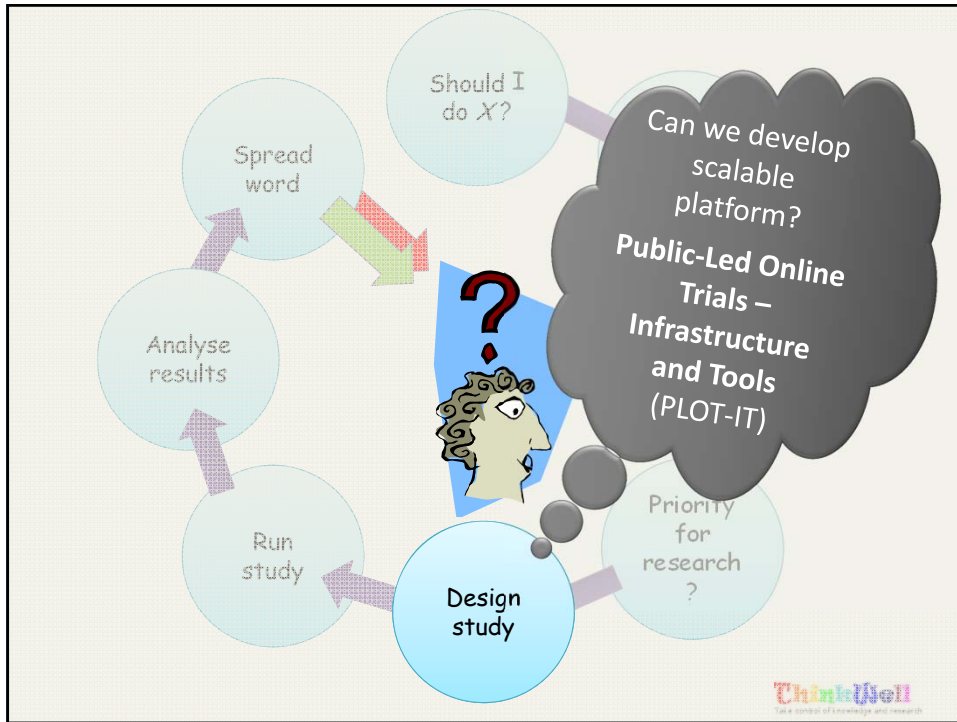


PsyWell – Internet recruited RCT of CBT delivered online for enhancing wellbeing

Date	Completed screening	No. consent emails sent	No. users consented	No. allocated to a condition (by consent date)
13-Sep-10	116			
14-Sep-10	164			
15-Sep-10	584	69	20	19
16-Sep-10	1682	197	99	94
17-Sep-10	397	260	139	129
18-Sep-10	199	1932	859	824
19-Sep-10	174	461	406	387
20-Sep-10	222	214	371	359
21-Sep-10	191	168	225	209
22-Sep-10	192	216	170	158
23-Sep-10	182	195	174	166
24-Sep-10	142	184	132	120
25-Sep-10	107	189	123	116
26-Sep-10	86	153	89	81
27-Sep-10	125	110	132	124
28-Sep-10 [*]	3	86	89	85
29-Sep-10		127	79	72
30-Sep-10		11	33	30
Total	4566	4572	3140	2973

^{*} Enrolment closed at 2am 28-Sep-10 (server time)
September 29, 2014





Methodological studies



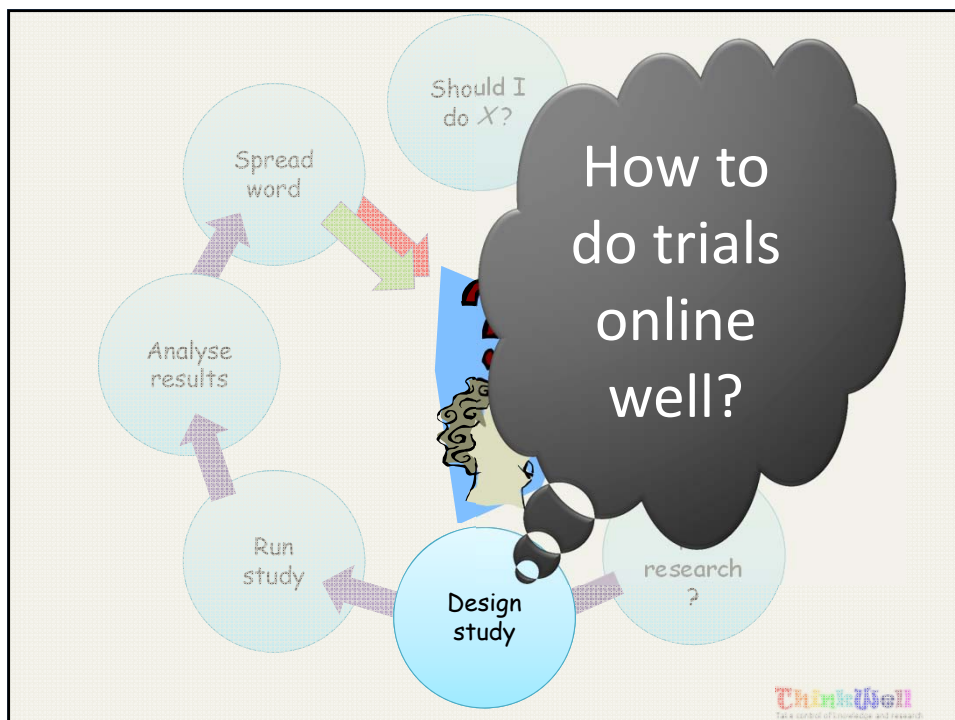
Online trial

- Results
- Number recruited
- What sort of people? (representativeness)
- Drop out rates
- Outcomes measured
- Cost
- Reliability of findings
- Participant experience

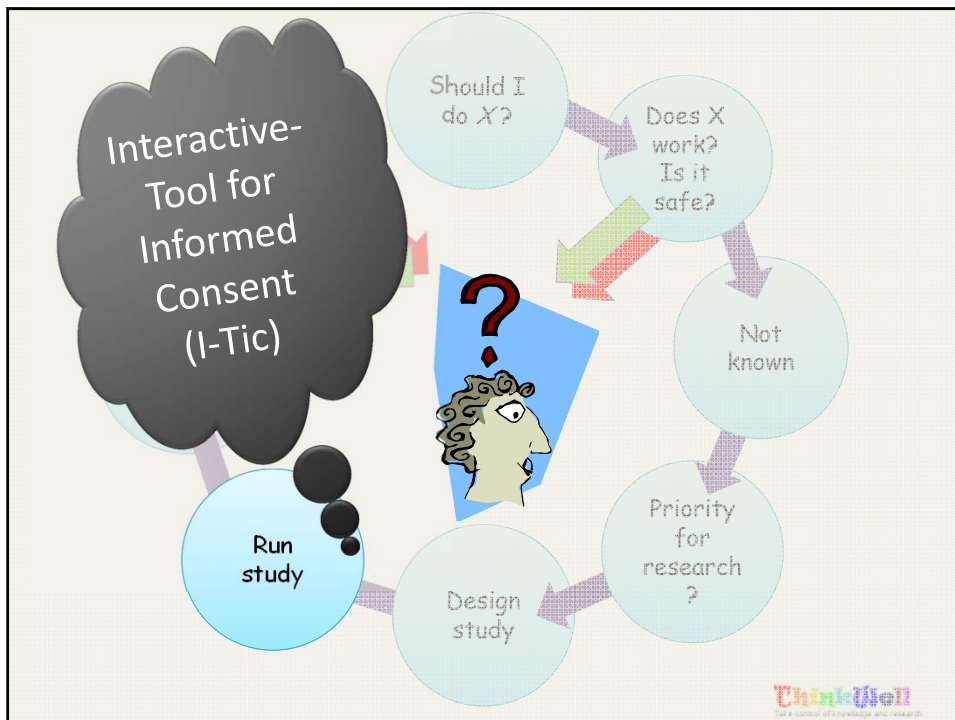
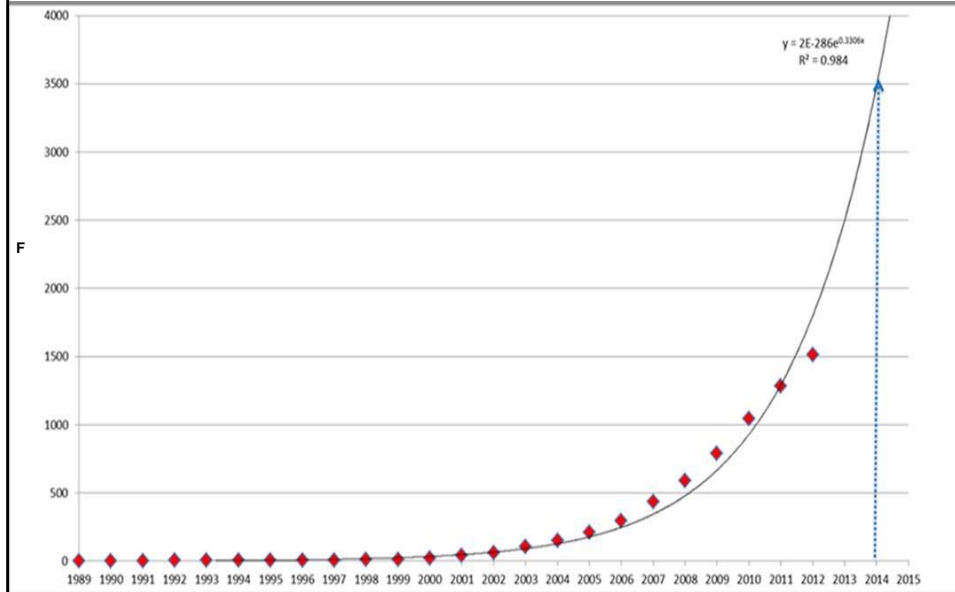
Standard trial

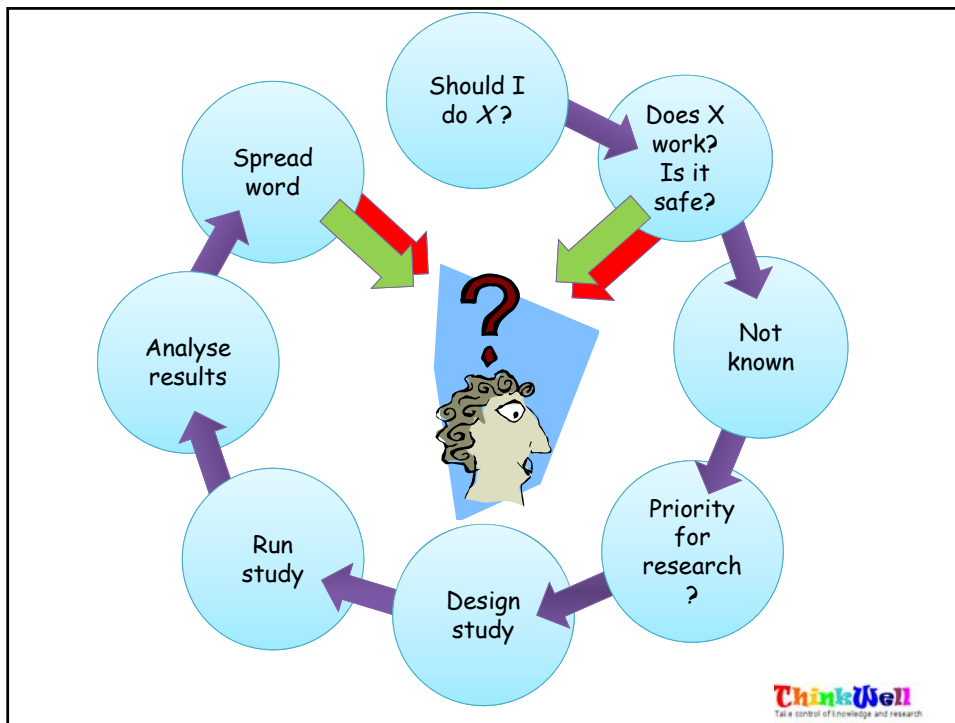
- Results
- Number recruited
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- Participant experience

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ORCHID – Online Randomised Controlled trials of Health Interventions Database





ThinkWell
Transforming health research

Dear Diet,
It's not me, it's you.
I just don't think it's
going to work between us.
You're boring, tasteless,
and I can't stop
cheating on you.

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Creating interventions

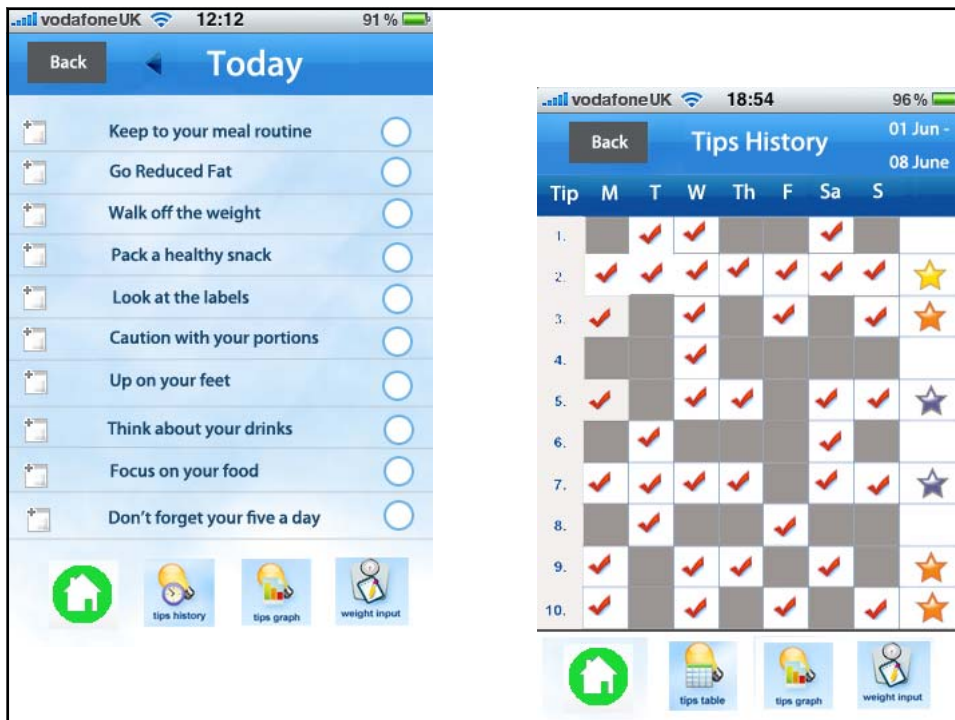
- Health app being trialled

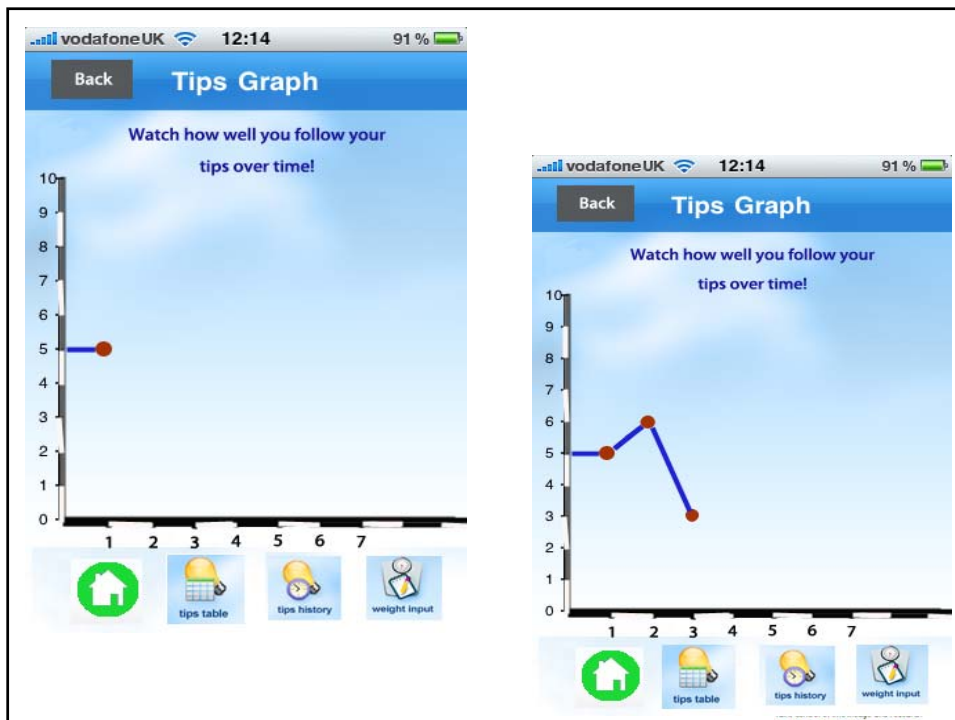
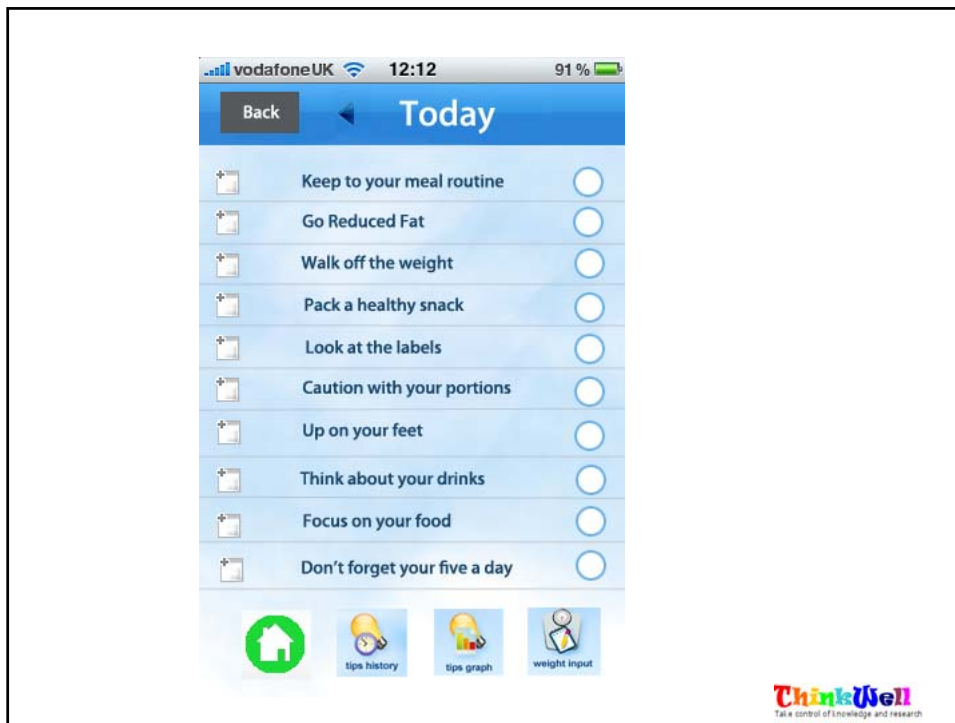
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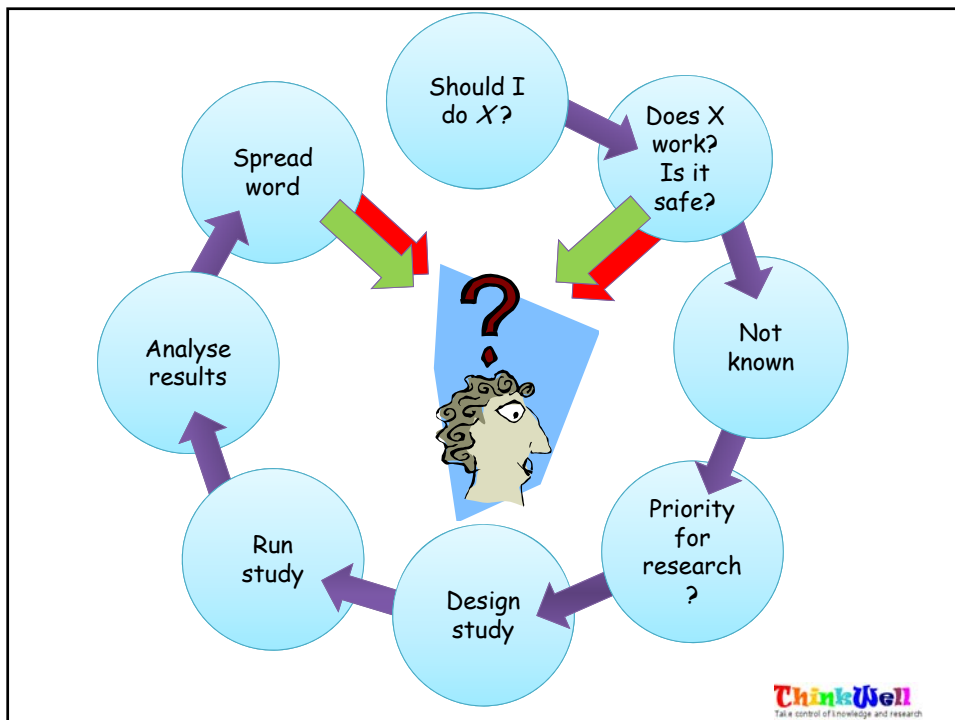
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“Why can't I choose which treatment to have?”



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Methodological studies



Online trial

- Results
- Number recruited
- What sort of people? (representativeness)
- Drop out rates
- Outcomes measured
- Participant experience

Online observational study

- Results
- Number recruited
- What sort of people? (representativeness)
- Drop out rates
- Outcomes measured
- Participant experience

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“Tell me and I will forget. Show me and I will remember. Involve me and I will understand. Step back and I will act.”

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*Thanks for
listening!*

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